

HOPE RITES

AN ETHNOGRAPHIC STUDY OF MECHANICAL HELP-HEART IMPLANTATION TREATMENT

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One part of my life is over, and the other one has not yet started, and I am nowhere, so how could anything happen to me in this mid-leap from what I was to what I am not yet? ... Everything familiar is left on the other side; this is the borderline between the years gone by and the life that awaits....

... Oh, delightful time, when I was a flying arrow shot through the spaces. Come back, time, to be an eternal glow, so that we don't have to count our losses on the fields of victory.

Mesa Selimović in *Silences* (translated by author)

We often spin like weathervanes, unsure of our positions, mad with insecurity.

Mesa Selimović in *Death and the Dervish*

Have you seen these totally mechanical hearts? It's unbelievable... It's fascinating! I hope they'll get there soon... as it is now you don't last for long with one of those. I really hope they can make it a good substitute for the normal heart.

Peter, a patient diagnosed with progressive heart failure

I was ill, got treated, and now I've gotten better again... so I'm not stuck in this clinical picture but live my life even more intensely... and that's why I get more and more problems... it's these encounters with health care that... that in my paranoid mind aim at detecting some little disease in me... so you look for what's sick, what's deviant, what's worse... and I can't live my life that way...

Niklas, former mechanical help-heart patient about his life after the treatment

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excruciating protracted fight for just one more last breath, slowly drifts away; or when a person facing a critical surgery – on a crossroads between life and death – invites you to take a look inside his or her widely open chest and behold that beating heart... up close; or when a young woman, sad, frightened, and baffled by her illness turns into a most sincere bright smile each time you enter her room; or when a woman, a mother and a wife, who always was so cheerful and positive, suddenly collapses in tears and cries for hours while holding your hands. My gratitude to all of you can never be expressed! May all your wishes come true and I sincerely hope our paths will cross again! For those of you who left before I got the chance to say goodbye, I'll see you in my dreams, where we are all kings and queens.

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Keep the height!

Haris Agić,

Linköping, February 2012

PROLOGUE

One November morning in 2008, Peter, a young man in his early thirties, who was diagnosed several years earlier with progressive heart failure, confided in me during his exercises at the hospital's physiotherapy and rehabilitation gym. He talked about the times when he used to be physically active – times when he practiced taekwondo, played badminton, and ran five kilometers five times a week. Peter was clearly nostalgic but tried at the same time to be rational about the limits his heart failure imposed on him. Therefore he sorted things into categories of 'what I can do' and 'what I can't do' accepting that taekwondo was out of reach for him. Still, he talked about dreams and how important they are although, he said, "They need to be kept in check and on a reasonable level".

To explain this statement Peter told me a story about a time when his friend, a psychologist, advised him to make a dream-list where he would write down everything he wanted to do in life. He said that the uncertainty of living with the heart in as poor shape as his worried him and also convinced him that he should not postpone things he would like to do. Hence, he wrote a dream-list for himself: pilot's certificate, diving certificate... Then, all of a sudden, between the heavy gasps for breath, while catching the big pearls of sweat with his white towel as they rolled down the bluish fields of his otherwise rather pale cheeks, Peter started chuckling, stretching his now dark-purplish, almost black, lips into a wide smile as he recalled how the person he contacted about the pilot's certificate laughed at him when he told him he suffered from heart failure. I asked if this made him sad. He said it didn't because "... sooner or later one needs to realize what can and what cannot be done and then you adapt".

For a heart failure patient, as Peters story shows, heart failure may not be something you *are* but rather something you *have* and/or something you *suffer* from. Heart failure, in this case, goes beyond signs, symptoms, and observable physiological deficiencies – it is an obstacle, a hindrance, a weight to be carried around, something you

need to adapt to, something that prohibits you from varied range of desired practices, something that narrows down your action space, something that calls for a 'reason' to stand in for 'emotion'. And inescapably, heart failure for Peter and many other patients suffering from advanced heart failure is something that might end your life at any given time.

The day before this, deeply impressed and full of admiration, Peter told me about a documentary he had seen on TV: "Have you seen these totally mechanical hearts? It's unbelievable... It's fascinating! I hope they'll get there soon... as it is now you don't last for long with one of those. I really hope they can make it a good substitute for the normal heart"¹.

¹ For detailed analysis of this episode see 'Destination hope' section (pp 194).

INTRODUCTION

If it wasn't for modern high-tech medicine and its power of always inventing new gleams of hope to light up the darkness for the hopeless, this would probably have been a book about people whose hearts have failed them, people facing the certain death. Therefore, besides being a book about people whose hearts have failed them and who are facing death, this is also a book about the biomedical professionals who give them hope of salvation and about the medical technology that enables these professionals to do so. Thus, this book is simultaneously about three seemingly different things. Yet there is a place where the edges of these three meet, which therefore also makes a suitable focal unit of analysis – namely the clinical practices through which the implantation of a mechanical help-heart is carried out.

While these new technologies save lives; they also bring new uncertainties, risks, and challenges. In the case of mechanical help-hearts, one such challenge is the sense of uncertainty evoked in the fragility of a sick person's condition on the one hand, and uncertainty evoked by the treatment with no warrant of success on the other. Although perhaps not so unique – as the common parlance has it: “in life, there are no guarantees” – this challenge is nonetheless real for the people whose lives are literally depending on this very success which cannot be warranted. What's more, instead of having a diversity of possible treatments this treatment is the only one at their disposal. In distinguishing between the source of uncertainty (life-threatening chronic illness) and means of dealing with it (mechanical help-heart treatment) we come across a paradox; the means of dealing with this uncertainty turn out to be yet another source of uncertainty. The question is, how is this dealt with?

Not only is this a matter of the power of biomedicine and of lives being saved, it is also about biomedical progress and the impact that this progress has on people. New technologies are often seriously contesting and overturning some of our deepest culturally established

postures². Hence, this thesis explores the forms of biomedical care that emerge with the ever-increasing development of various medical technologies for treatment of heart diseases.

I look at these clinical practices as rituals. Healing rituals are anthropologically well-documented ways in which any social group deals with dangers, uncertainties and misfortunes that threaten their world³. Traditionally, anthropological studies of healing rituals focused on small-scale premodern societies. Perhaps the principal difference between these healing rituals and modern biomedical care lies in the evidence-based approach of the latter paired with the asserted empirical traceability of its workings. However, there are still limits to what can be biomedically known – which is why no warrant of success can be offered to mechanical help-heart patients. Everything takes place as if uncertainty is a fundamental element in all human practice devoted to dealing with misfortune such as life-threatening chronic illness. In the case of mechanical help-heart treatment, various pragmatic strategies are developed as means of dealing with the ever-present threats of indeterminacy.

My aim here is to explore ethnographically the cultural aspects of mechanical help-heart treatment as a modern biomedical healing ritual. I seek to understand how the ways in which these clinical practices are structured and performed tie into the shared understandings about life threatening chronic illness, the body, and medical technology. Moreover, by discerning what kind of challenges emerge with the performance of mechanical help-heart treatment, I also ask how these challenges are understood and managed.

Ritual theory is particularly useful in unlocking the details of these strategies as it provides analytical keys “... to the understandings of how people think and feel about [their economic, political, and social] relationships, and about natural and social environments in which they operate” (Turner 1997[1969]: 6).

² I will return to this subject shortly with several examples in ‘As heart became pump’ section (pp 3-7).

³ See CHAPTER THREE – THEORETICAL FRAMEWORK (pp 121).

Anthropological accounts of healing rituals show that humans always and everywhere have sought to understand the sources of their ill health and have also adopted various means of dealing with them. What is it, then, in these practices, that has essentially changed with the emergence of modern medical science and biotechnology and what has remained the same?

As modern hospitals, concrete places where medical science and technology are put into practice, are essentially places of transition where people go to get better and to eventually return to their normal lives, a comparison with healing rituals of social transition, i.e. *rites of passage*⁴ through which a person is transformed from 'ill' to 'healthy' (or from 'defect' to 'restored' etc) is of particular interest. Therefore, I use the concept of ritual as an analytical key to reveal and make sense of social and cultural dimensions of hospital treatment in the case of mechanical help-heart implantation.

⁴ For detailed definition and account of rites of passage see 'Rites of passage' section in CHAPTER THREE – THEORETICAL FRAMEWORK (pp 143).

PART I

PART I of this tripartite thesis⁵ consists of three introductory chapters which will account for the contextual background of the study, an overview of previous research as well as for theoretical and methodological concerns.

In CHAPTER ONE – BACKGROUND, I open with a brief presentation of cultural aspects of the human heart and continue with brief historical overview of heart-related illness throughout the latter half of the past century. Here I will also describe the development of main biomedical strategies of dealing with heart-related illness and of medical technology in its service. Finally, I will provide a brief account of previous research significant to this study. This contextual introduction will then be rounded off with aims and research questions.

CHAPTER TWO – METHOD is a methodological chapter where I will describe my own experience of, as well as terms and conditions that surround the nine-month long fieldwork conducted in a modern university hospital. Moreover, I will in this chapter also account for how I approach the analysis of collected ethnographic data.

CHAPTER THREE – THEORETICAL FRAMEWORK is the last chapter of PART I and will be devoted to description and discussion of the theoretical approach that I have chosen to work with. Moreover, a number of concepts central to this framework which are also significant for the purposes of this study will be addressed and discussed.

⁵ For the disposition and contents of the whole thesis see 'Structure of the thesis' section (pp 59). For PART II see pp 167, and for PART III see pp 363.

CHAPTER ONE – BACKGROUND

I

THE HEART IN HISTORY

AS HEART BECAME PUMP

The human heart has always and in all known cultures enjoyed the status of one of the most fundamental symbol-bearing body parts, representing love and hate, courage and fear, joy and suffering, good and evil, strength and weakness. It has been seen as the sheer source of life and the ego, i.e. the subject or the self (Høystad 2007; MacPhee 2003; Turner 2003; Wikan 1989). Values, emotions, attitudes, and outlooks that are attributed to the heart are always intimately connected to the encompassing cultural contexts (Høystad 2007). The heart contains feelings and yearnings and can break; the heart is also the source of strength, courage, and fearlessness (a big heart). The heart allows for or denies empathy and sympathy (good-hearted, heart of stone, a mother's heart). The heart is a pin cushion, a fountain, a house, and a picnic spot (Young 2002). The heart is also intelligent; not only does it sense, but the heart knows – and that prior to the cerebral cognition, (Alberti 2007: 125; Reeves 2003). It also serves as storage house for knowledge (learning by heart). The heart can be given away as a sign of love. It can be won over, conquered, or caught as a proof of charming powers. It can be opened up as the cover of an old book, as a sign of honesty. It can harbor the deepest of the secrets, but also delight, desire, worries, and aversion. It can fly, sink, grow, faint, bleed, flutter, burn, rejoice, fibrillate, stop, fail (Young 2002). The heart can attack. The heart is also used to symbolize the very core of something – in the heart of the city, the heart of soul, the heart of the land, in the heart of the earth (Høystad 2007). The heart is deliberately being managed to brighten face and soul (Wikan 1989). A weak or anxious heart might make you sick. The heart is also to be nurtured with “medicine for the heart” as, for instance, in the

Moroccans' deliberate stirring up of an emotional reaction through audio exposure to the melody of professional citation of Koranic verse until the fulfilling bodily sensation in and around the heart is reached (MacPhee 2003).

In contemporary biomedicine, the heart is anatomized; it is an apparatus, a piece of equipment (Guillemin 2004; Høystad 2007) the size of a clenched fist, lying under the sternum, between the lungs. It is made up of four chambers – one left and one right ventricle, and one left and one right atrium. Actually, it is not one pump, but consists of two pumps – one left and one right. They are made of muscle and move blood around the body. The left side is the systemic heart, bigger than the right side, and sends an impressive 2000 gallons of blood through the 60 000 miles of vessels in the body each day (Young 2002). The right side is the smaller one and sends blood through the lungs – pulmonary circulation. The heart's contraction phase is called systole. In-between two systoles the heart is at rest. This relaxation phase is called diastole. The average heart beats between 50-100 times per minute (Persson and Stagmo 2008).

In his contribution to the anthology *The Heart* (Peto 2007), Jonathan Miller, himself a physician, provides an interesting discussion of the ways in which our various understandings and conceptualizations of human heart has been tied to the surrounding technological development (Miller 2007). He tells us that during the pretechnological era, and also in contemporary societies where technological metaphors are few and simple, explanatory metaphors were sought in the directly observable natural phenomena, such as wind, water, breeze, tide, flood, storm, earthquake, fruit, and animals. Throughout history, the technological development created a continuous increase in metaphorical expressions which helped us humans make sense of our world and of our being in the world (Miller 2007). These new – technological – metaphors offer symbols and images, the logical character of which is completely different from that of the old ones. By creating the tools that performed jobs – such as bows, boilers, oven, axes, and carts – humans became

increasingly dependent on these new mechanisms, the success of which, in turn, depended on the efficiency of their working parts. “By mechanizing his practical world, man inadvertently paved the way to the mechanization of his theoretical world” (Miller 2007: 45). The technological symbolical expressions are frequently used as explanatory models for our thinking about humans and the human body in particular, as it is often depicted both as a battle ground (using the metaphor of the techniques of warfare) and as a machine (using the jargon of engineers) (Coulehan 2003). These expressions have to a great extent influenced the ways we view and understand ourselves. Whatever it may be that these various machines and mechanisms – telecommunicating technology and infrastructure, inventions of a steam machine, a space shuttle, a computer, the Internet, a submarine – were designed to perform, they have also provided us with hypothetical models – metaphors – through which we seek to understand how the human body works.

It took us a long time before we started to think of the heart as a pumping muscle that moves blood around the body (Young 2002). Bodies of the living couldn't just be sliced open to see what's inside. This left us with the bodies of the dead. The bodies of the dead were, however, taboo for many. Consequently, it was butchers and priests who had access to the insides of animals. At the same time, they were not interested in anatomy other than to provide proper cuts of meat, or to please the gods with the sacrifice. The ancient Egyptians, on the other hand, observed a somewhat different kind of taboo regarding the sanctity of a dead body. They didn't believe the body could be resurrected, which allowed them to cut into it in order to prepare it for eternity – a practice known as mummification. Still, in spite of their sophisticated surgical practices, they weren't interested in the uncovering of the secrets of the body. Through these practices, they identified the heart, the vessels and the pulse, without making any serious attempt of analyzing their workings. They believed that vessels carried air throughout the body. Atharvaveda, the ancient Indian text dating back to 1200 BC, i.e. 2500 years before William Harvey's

Exercitatio Anatomica de Motu Cordis et Sanguinis in Animalibus (An Anatomical Exercise on the Motion of the Heart and Blood in Animals, published 1628), reveals some ideas about blood actually moving inside the vessels. Ancient Chinese medical texts from some 3000 years ago mention pulse and the significance of pulse. Still the heart is described as a divinely inspired part and is ascribed the role of the king or master in charge of blood (Young 2002). Ancient Greeks have also identified the organs inside the thorax and abdomen and even observed that the blood moves inside the vessels. Still, they didn't manage to bring these observations together in their mechanic coherence. Galen spoke of the heart as a lamp that was injected with an oily substance – the fuel – from the liver. The Persian scholar Ibn Sina (978-1036) suggested that the heart was the first organ to be made; the left side of the heart is made by God to both store and to manufacture *breath* or the *vital force* (Ibn Sina 1999[1025]: 144, 145). Furthermore, the heart, according to Ibn Sina, acts through other organs – through the brain for mental functions and through the liver for nutrition (Young 2002).

So why did the circulation and pumping function of the heart remain a mystery for so long? Some say that this depends on the absence of adequate metaphors which could help us think – to imagine – that which is usually a property of vision (Miller 2007). For instance, Galen spoke of the heart as a lamp and blood as fuel. The heat, or fire, inside the heart consumed the fuel (the blood), refining it in the process. Thus, the heart was similar to a furnace or a boiler, the purpose of which was to burn the impurities in blood that were caused by food (Alberti 2007). Galen's theory made sense of other ancient theories, structuring them in a comprehensive system that resembled something between brewery and furnace. The vessels could then easily be compared with industrial pipes. This theory was, nonetheless, clearly relying on technological terminology, and the performance of the heart consisted of production, transformation, boiling, brewing, and melting – all the processes which cleanse and refine crude material substances (Alberti 2007; Miller 2007).

The fact that the heart's pumping role in the circulatory flow of blood through the body wasn't acknowledged until one and a half millennia later indicates that Harvey and Galen used different metaphorical explanatory models, or tools. Galen systematized the results of his observations in accordance with the world he lived in. The analogies available were lamps, ovens, breweries, etc. His failure to see the pump in the heart were probably due to the fact that the pump as a technological innovation didn't become a significant part of the cultural arena until much later, after his time. Harvey, on the other hand, lived in the late 16th and early 17th centuries. This was a time when the level of technological development – observable in existing industrial machines and complexes, and also in activities such as fire fighting and the art of civil engineering – made the pump, as a mechanical system, a firmly established technology in society. Harvey's theory, in which the pulsatile qualities of the heart were depicted as the mechanical qualities of a pump, opens up a whole new field of medical practices to come –even to the present day when parts of the human heart and even whole hearts are being replaced by their mechanical replicas. The mechanical view of the function of the heart that Harvey assumed made it possible for mankind to begin thinking about a mechanical substitute for the real heart. Various meanings that we ascribe to this remarkable organ are continuously being contested by the development of new technology and new cultural, metaphorical expressions we use in our attempts to understand it. Considering this, it seems as if the influence that technological development has on the ways in which we think of human body might be more far-reaching than anticipated. For instance, technical advances that made transplanting the heart possible also brought about some very deep institutional, conceptual, and cultural changes. In fact, they caused a fundamental re-evaluation of what signifies the time of death, which should serve as a good example of the influence that technological progress has on our understanding of, and our being in, the world.

II THE HEART TODAY

ENDEMIC PROPORTIONS OF CARDIOVASCULAR DISEASES (CVD)

Today, the heart seems to be carrying the weight of modernity and globalization (Beaglehole and Yach 2003). As the people in the Western world live longer, heart-related diseases are reaching endemic proportions. Just in the United States about 81,100,000 individuals are estimated to suffer from cardiovascular diseases (CVD) – that is more than every third citizen. Of these, 5,800,000 are heart failure patients (Lloyd-Jones, et al. 2010: 56). One of almost every three deaths in the US in 2006 was caused by cardiovascular diseases; “Nearly 2300 Americans die of CVD each day, an average of 1 death every 38 seconds. CVD claims more lives each year than cancer, CLRD [chronic lower respiratory disease], and accidents combined” (Lloyd-Jones, et al. 2010: 57).

On the other hand, the public health activism in the middle of the last century in the developed world has initiated large-scale health promotion actions and campaigns with the objective to “... reduce unhealthy behavior, improve preventive services, and create a better social and physical environment” (McAlister, et al. 1982: 43). These are usually referred to as ‘community-based noncommunicable disease interventions’ (Nissinen, et al. 2001) or ‘comprehensive community programs for health promotion’ (McAlister, et al. 1982). Some of the most renowned projects in Europe during the 1970s are the North Karelian Project in Finland, The Schlitz Project in the German Democratic Republic, the Eberbach-Wiersloch project in the Federal Republic of Germany, the Martignacco project in Italy, the Finnmark and Tromsø studies in Norway, and the Novi Sad Program in Yugoslavia (Puska, et al. 1988). In the US a similar development took place resulting in the Framingham Heart Study, the Stanford Five-City Project, the Minnesota Heart Health Program, and the Pawtucket Heart Health Program (Bukhman and Kidder 2008; Nissinen, et al. 2001). During the 1980s the regional offices of WHO

carried out a number of projects, including the Countrywide Integrated Noncommunicable Diseases Intervention (CINDI), the Collaborative Action For Risk Factor Prevention & Effective Management of Chronic Diseases (CARMEN), and the Interhealth Program (Nissinen, et al. 2001).

Overall, these programs have eventually resulted in a prognosis that estimating between 1990 and 2020 a 14.3% reduction in the numbers of years of healthy life lost due to CVD is expected in the developed world while in developing countries during the same time period a 55% rise will occur (Murray, et al. 1996; Reddy 2002). In other words, during this period "... mortality from ischemic heart disease in developing countries is expected to increase by 120% for women and 137% for men" (Yach, et al. 2004: 2616). "CVD-related deaths in India are expected to rise from 24.2% in 1990 to 41.8% of total deaths in 2020. Thus, the increasing burden of CVD will be borne mostly by the developing countries in the next two decades" (Reddy 2002: 232).

CVD AND FREE TRADE

This turnabout is mainly due to the recent development of the global state of affairs regarding finances, trade, and power relations, which is having a significant impact on the development of CVD epidemics (Woodward, et al. 2001). The pace of financial globalization, together with the free trade rules imposed by the World Trade Organization (WTO) can incite economic growth and thereby also aid population health status – yet this has not been the case for the poorest, a.k.a. the Least Developed Countries (LDC)⁶ (Beaglehole and Yach 2003; UNCTAD 2009). On the contrary, the global rules and power imbalances hold back the poor countries' abilities to take adequate action regarding increasing CVD problems. The UN Report claims

⁶ Forty-nine countries are currently named by United Nations as 'least developed countries' (LDC). These are distributed among the following regions: Africa (33 countries), Asia (10 countries), Pacific (5 countries), and the Caribbean (1 country). (URL: www.unctad.org – on April 21st 2010)

that the least developed countries are even more exposed to external shocks than the developed ones (UNCTAD 2009). Agricultural subsidies in developed countries eliminate all the competition from primary producers in developing countries, which is having a direct and severely negative impact on these countries' incomes.

Exporting culture – exporting health risk

Modern means of communication have expanded global marketing. Today, Western tobacco, alcohol, salty, sugary, and fatty foods are reaching nearly every corner of the globe. This means that while people in the developed world are increasingly complying with the large-scale prevention programs and thereby reducing their consumption of tobacco, alcohol, salt, sugar, and saturated fats, the producers of these products have shifted their focus towards another target group – people in the developing world. Traditional diets rich in fruits and vegetables are being replaced by fast food culture and mass-produced food items based on animal fats and fast carbohydrates all over the world (Beaglehole and Yach 2003). In fact, it has been argued that the “US model is now being exported around the world and has met with great success in producing obesity everywhere it has been tried” (Hill, et al. 2000). Global economic growth, brought about by the neo-liberal model of free trade, has also incited increased consumption of tobacco, alcohol, and salty, sugary and fatty foods in developed countries. The main actors here are transnational corporations:

Several of the world's top 100 nonfinancial transnational corporations ranked by foreign assets in 2000 are associated with chronic disease risk factors, including tobacco, food, and automobile companies. These companies all invest heavily in marketing their products, which, if unregulated, encourages acquisition of the risk factors for chronic diseases. (Yach, et al. 2004: 2620).

The risk factors named above are, through persistent health promotion programs, a subject of control in the developed world. At the same time, the risk factors are exported to the people in the developing world – exporting the Western way of life also means exporting risk factors and CVD. Back home, besides the triumph of prevention programs, the progress of Western medicine is significantly reducing the mortality from a vast number of cardiovascular diseases and hence increasing the overall life expectancy in the developed world. This is due to the kind of resources – money, technology, facilities, drugs, etc. – that are still lacking in the developing world.

THE TRIUMPH

Above all, the mortality in cardiac infarction – heart attack – has been reduced drastically with the development of pharmaceutical technology⁷, as well as various surgical techniques such as angioplasty and bypass surgery. However, a survived heart attack damages, in many cases, the heart muscle significantly – a desired progress backfires. WHO's report, *Global burden of ischemic heart disease in year 2000* shows that around 20% of the victims of survived acute heart attacks end up developing congestive heart failure (Mathers, et al. 2000: 15). Thus, what might seem as a paradox, the number of patients diagnosed with congestive heart failure increases with the increasing number of heart attack survivors, “The number of HF [heart failure] deaths has increased steadily despite advances in treatment, in part because of increasing numbers of patients with HF due to better treatment and ‘salvage’ of patients with acute myocardial infarctions (MIs) earlier in life” (Hunt, et al. 2005: 157). A British Heart Foundation report, *Coronary heart disease statistics: heart failure supplement* from 2002 states that “... as the UK population ages and more people survive heart attacks, the number of people with heart failure is likely to increase substantially, creating a major burden for the National Health Service” (Petersen, et al. 2002: 05). Also other

⁷ Such as anticoagulative, vasodilating, and anti-arrhythmic medications

heart-related diseases, such as defective valves, arrhythmia, high blood pressure, and heart muscle diseases, that today no longer are lethal in the Western world thanks to the progress of Western heart medicine, are recognized as the underlying cause behind a great deal of heart failure diagnosis. In this day and age, the prevalence of heart failure is estimated at 1-2% among the people in developed countries with incidence approaching 5-10 per 1000 persons every year (Mosterd and Hoes 2007: 1139).

THE SIDE EFFECT

The increased overall life expectancy in the developed world is contributing to the continuously rising incidence of heart failure. Mosterd and Hoes write in their article *Clinical epidemiology of heart failure* that heart failure is seldom found among persons younger than 50 years, whereas among those older than 50 years "... the prevalence and incidence increase progressively with age" (Mosterd and Hoes 2007: 1139). Furthermore, they warn that "... the ageing of the population in combination with improved prognosis fuel the heart failure epidemic" and suggest that the "prevention of the occurrence of heart failure is needed to stem the epidemic" (Mosterd and Hoes 2007: 1142). Hence, it is quite clear that heart failure is "a condition of the elderly" – the incidence of heart failure rises up to 10 per 10,000 people older than 65 (Hunt, et al. 2005: 157).

PANDEMIC PROPORTIONS OF HEART FAILURE

According to WHO's report *The global burden of disease: 2004 update* the global incidence of heart failure is 5.7 million new patients each year (Mathers, et al. 2008: 28). These 5.7 million are distributed across the following regions in this pattern: 500,000 in Africa, 800,000 in North and Latin America, 400,000 in Eastern Mediterranean, 1.3 million in Europe, 1.4 million in Southeast Asia, and 1.3 million in the Western Pacific (Colin Mathers, et al. 2008).

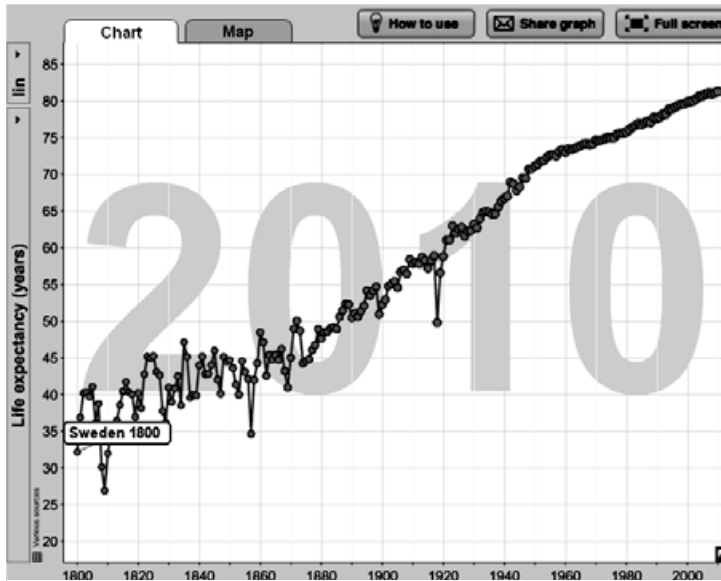


Figure 1: Life expectancy trend in Sweden from 1800 to 2007 (source: www.gapminder.org)

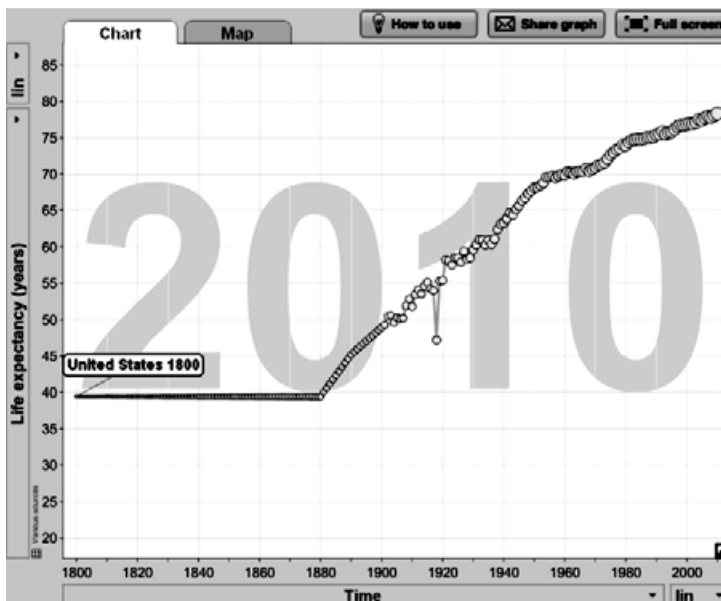


Figure 2: Life expectancy trend in the US from 1800 to 2007 (source: www.gapminder.org)

Each year there are 550,000 patients in the United States who are diagnosed with heart failure for the very first time (Hunt, et al. 2005: 156). One in eight deaths has Heart Failure mentioned on the death certificate; “HF was mentioned on 282,754 US death certificates and was selected as the underlying cause in 60,337 of those deaths” (Lloyd-Jones, et al. 2010: 130). During 2001 only about 53,000 of US citizens died of HF as a primary cause (Hunt, et al. 2005: 157), whereas one of five Americans with heart failure dies within one year after being diagnosed (Lloyd-Jones, et al. 2010: 131).

The Rotterdam prospective population-based cohort study (Bleumink, et al. 2004) shows that one in three individuals aged 55 “will develop heart failure during their remaining lifespan” and concludes that “[h]eart failure continues to be a fatal disease, with only 35% surviving 5 years after the first diagnosis” (Bleumink, et al. 2004: 1614). In the United Kingdom there were in 2002 nearly 900,000 people with definite or probable heart failure, almost 40% of whom die within a year (Sophie Petersen, et al. 2002: 06). Furthermore, hospitalizations due to heart failure are expected to increase by 50% during the next 25 years (Sophie Petersen, et al. 2002: 06) – a prognosis showing just how fast heart failure is reaching endemic proportions.

III

HEART FAILURE AND MEDICAL TECHNOLOGY

PROGNOSIS

The prognosis of heart failure patients remains poor in spite of the array of both pharmacological and non-pharmacological biomedical treatments available (Mosterd and Hoes 2007: 1142). In fact, it is said that “... heart failure severe enough to require hospitalization is more ‘malignant’ than many of the common types of cancer” (Stewart, et al. 2001: 321). In Sweden, cardiovascular diseases are the largest cause of death, heart failure being one of the most severe and most common among them. The mortality rate of heart failure is on an equal footing

with several cancer diseases (Hont, et al. 2007). During the year 2010, nearly 3989 people in Sweden – 2389 women and 1609 men – died because of heart failure (Socialstyrelsen 2010a). Persons with end-stage heart failure face death if they don't receive a new healthy heart. In general, around 30% of patients on waiting list die before transplantation (Peterzén 2001). Due to such a high mortality rate and also to the growing gap between numbers on waiting lists and the numbers on donation lists, in Sweden as well as elsewhere, the focus is increasingly being directed towards new medical technology.

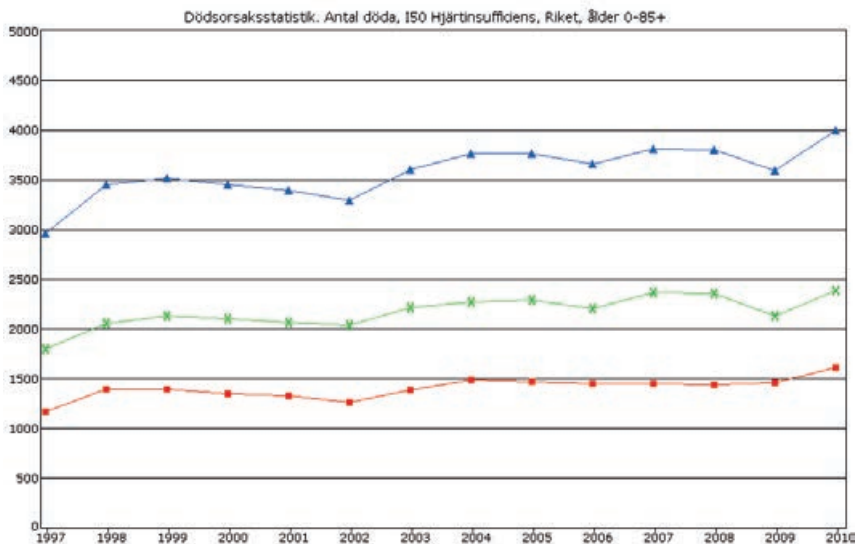


Figure 3: Mortality rate of heart failure in Sweden, countrywide, ages 0-85+ (green - female sex; red - male sex; blue - both sexes). (Socialstyrelsen 2012)

TECHNOLOGICAL SOLUTION

In the age of failing hearts, mechanical ones are increasingly being implanted in the bodies of the chronically ill and the dying with the aim of prolonging their lives (see Table 1). In Sweden only, during the ten years between 1998 and 2008, a total of 362 extra- para- or intracorporeal ventricular assist devices have been implanted into patients with a failing left ventricle – 16 of which were implanted in

1998 while in 2008 a total of 66 machines was reached (Socialstyrelsen 2010b).

Left Ventricular Assist Devices (LVAD) – also referred to as mechanical help-hearts, or in professional daily discourse “The Pump” – support the heart’s failing left ventricle. These devices are developed with the aim of surmounting the problem of dependence on real hearts. In addition to being implemented as bridge-to- being

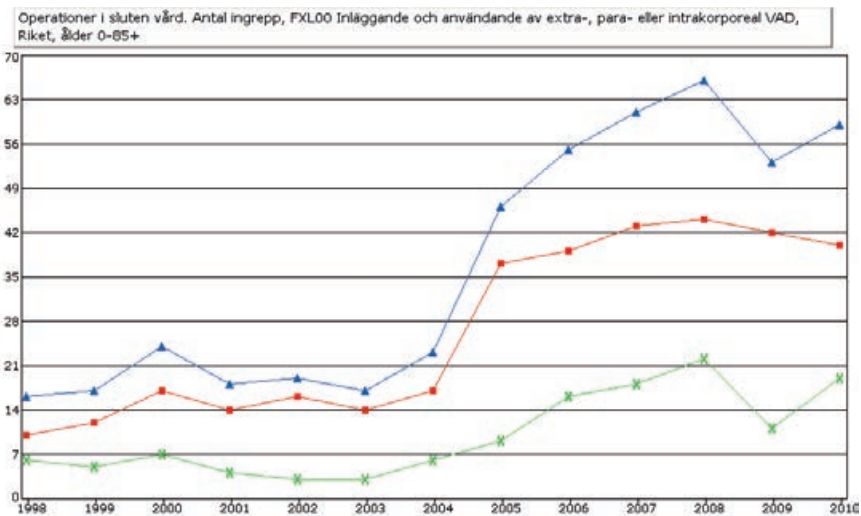


Figure 4: Number of operations in Sweden, FXLOO Implants and use of extra-, para-, or intracorporeal VAD countrywide, ages 0-85+ (green - female sex; red - male sex; blue - both sexes). (Socialstyrelsen 2012)

transplant time-buying life-savers, these devices are more and more envisaged and tested as ultimate substitute for heart transplantation. The latest advances in medical technology make the human heart completely replaceable with a mechanical, i.e. artificial one. However, future prospects of the clinical efficiency of artificial hearts are still uncertain (Waldenström 2008). Be that as it may, the dramatically low survival rates among patients with implanted LVADs indicates a frail existence in burdensome uncertainty (Lietz 2007, see Figure 5).

Heart failure is connected to biomedical technology in at least three ways. First, heart failure is a chronic illness, the treatment of which involves utilization of a multitude of medical technologies. The

technological palette deployed ranges from telemetrically monitored heart beats or frequent electrocardiography (ECG) to visualization technologies such as ultra-sound, x-ray, and coronary angiography, computed tomography. It includes implantation of various heart assist devices (HADs) such as pacemakers and cardioverter-defibrillators, as well as various surgical procedures involving opened chests, heart-

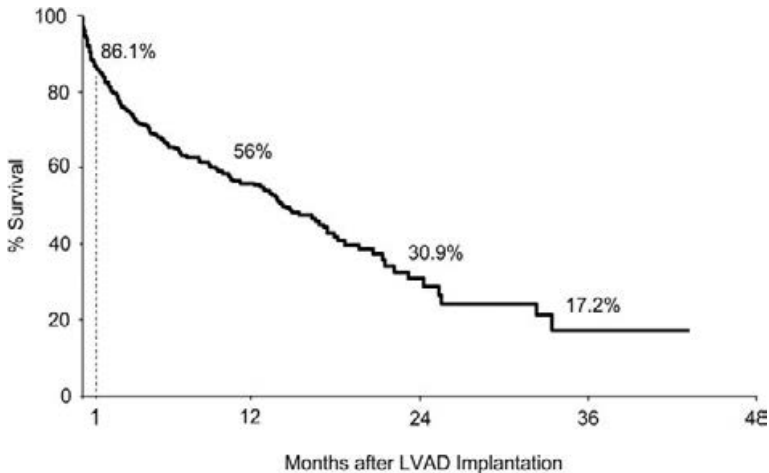


Figure 5: Survival after LVAD implantation (Lietz 2007)

lung machines, punctured and cut vessels, bypassed arteries, sewn up valves, pulmonary artery catheters, mechanical ventilation, monitoring equipment, intravenous lines for drug infusions fluids, suction pumps, drains, scalpels, electrical saws, graspers, clamps, retractors, trocars, and dilators. It also includes the life-support systems of intensive care medicine, and ultimately mechanical circulatory support (MCS) systems such as the Left Ventricular Assist Device (LVAD) and the Total Artificial Hearts (TAH). Second, the chronic character of heart failure also means that patients will have life-long dependence on some of these technologies (for example, to various extents, implanted pacemakers, defibrillators, and sometimes also mechanical help-hearts) or at least inevitably have recurrent confrontations with others (such as ultra-sound, electrocardiography, x-ray, and surgery). Third, mechanical help-hearts represent "... a continuity of clinical

dream, totally replaceable body [and are] key symbols of [Western] medicine's progress against death", (Plough 1986: 4). The first artificial kidney that could be used on humans came about in 1943. The first heart-lung machine appeared in the early 1950s, indicating that the heart's circulatory function can in fact be substituted. From that point onwards, the idea of creating a total artificial heart seemed not only viable; it became highly desirable. In addition to all this high-tech, high-end and biomedical expertise and knowledge, what makes the study of end-stage heart failure and implantation of mechanical help hearts even more interesting is the fact that the human heart has, always and in all known cultures, enjoyed the status of the most symbol-bearing among the body parts.

Hjärtpump – 'mechanical help-heart' technology

While most articles and books on medical technology, within humanities and social sciences, tend to end by referring to artificial organs as the newest technology, I make this subject matter the very point of departure of this enquiry. Indeed, functional extension of the human body beyond its boundaries is nothing of a novelty. Everything from external prostheses, artificial limbs, wheelchairs and crutches, hearing aids, and glasses to dialysis equipment and breathing apparatus witness to the broad spectrum of technological innovativeness when it comes to extending the bodily confines. The mechanical help-heart technology seems, however, to stretch both beyond the Vitruvian notion of a machine as being merely a tool for moving heavy objects, i.e. a man-made artificial assistant, as well as beyond the modern notion of a machine as totally replacing the muscular effort of human labor (Gramsci 2007[1975]: 105, 287). This expansion is not inherent in mechanical help-heart technology in and for itself but comes about in practices of implanting it into the human body – the body in and through which this technology is no longer merely used but lived.

In light of this, the practices of implantation through which these apparatuses are made part of the human body raise the question of to

what extent – if at all – the official umbrella terms such as “Heart Assist Device” (HAD) or “Mechanical Circulatory Support” (MCS) are appropriate. The mechanical help-heart differs from other external technologies in that it is placed inside the body, which puts it in the same group as other implantable devices such as joint replacements, breast implants, pacemakers, and cardioverter-defibrillators. Yet beyond being merely implantable, the mechanical help-heart is also a dynamic mechanism, i.e. a motoric machine or mechanism performing animate physiological function, unlike all the other non-motoric implants (Brown and Webster 2004). This, nevertheless, doesn’t seem to successfully distinguish the mechanical help-heart from other dynamic technologies such as cochlear implants, various drug delivery devices, and pacemakers. Certainly, unlike these, the mechanical help-hearts belong among those technologies that are capable of postponing imminent death. However, so do a number of other motoric implantable devices, such as pacemakers and implantable cardioverter-defibrillators. What’s more, this characteristic tends to group HAD technology together with technologies such as organ transplantation and various other lifesaving surgical techniques, while it brings it back to the cluster of so-called life-sustaining technologies such as hemodialysis, machine-assisted breathers (pulmonary resuscitators), automatic cardiopulmonary resuscitation (CPR) machines, and heart-lung machines.

Everything takes place as if the uniqueness of mechanical help-hearts is not to be found in one particular quality as each feature, when considered in and for itself, tends to place the HAD on a par with some other comparable technologies. Instead, it is a multilayered composition of its own intrinsic qualities that pushes mechanical help-hearts between and beyond, although also slightly overlapping with, a multitude of other medical technologies:

- i. The mechanical help-heart is a technological innovation deployed to delay impending death.

- ii. The mechanical help-heart is a corporal device, i.e. it is connected to the body.
- iii. The mechanical help-heart is an implanted device, i.e. it is placed inside the body.
- iv. The mechanical help-heart is an implanted motoric device, i.e. it compensates for the failed animate bodily function.

The fifth, and perhaps most important quality, would rise from the recognition of the mechanical help-heart as a technological replica of one of the most central vital parts of human body. In fact, the centrality of the human heart goes beyond its key physiological functionality and includes the spatiotemporal universality of its symbolical power (see *The Heart in History* section, pp 3-7). Thus, the achieved replication of this physiological and dynamic organ automatically also entails what might be seen as: 1) conversion of its concrete material existence – from human flesh to smooth titanium, 2) transformation of its functional form – from substantial muscle to mechanical pump, and also 3) reification of its emblematic imagery – reducing all the heart’s meanings to just one, although twofold, physiomechanical/biotechnological one.

Technicalities

The first successful implantation of a Left Ventricular Assist Device, an early pulsatile intrathoracic pump, was done in 1961 by American surgeon Domingo Liotta (Bronzino 1995; Liotta, et al. 1963). This was a pneumatic air pump – an early predecessor of the contemporary electrically powered axial flow impeller. The particular mechanical help-heart that was used in the hospital where I have conducted my field work was HeartMate II®. This is a little pipe of titanium containing a small spinning rotor– a single moving part of the device – with capacity from 6,000 up to 15,000 rpm. Or in other words, it is easily capable of pushing up to 10 liters of blood from the heart’s left ventricle throughout the whole body, per minute – a measure usually

referred to as the full output of a healthy heart. A coin-sized hole is made by surgeon in the left ventricle's apex, onto which the 'inflow conduit' (a flexible pipe) is sewn. Then, another hole is made in the ascending aorta onto which the 'outflow elbow' (another flexible pipe) is sewn.



Figure 6: HeartMate II (Reprinted with the permission of Thoratec Corporation)

The entire internal blood-contacting surface of the pump is textured, i.e. specially designed to prevent blood clotting. HeartMate II® is placed inside the chest, underneath the heart, above the diaphragm. The older model of this machine, the HeartMate I® was much too big to fit above the diaphragm and was thus placed in the abdomen – a solution that caused patients a great deal of pain. The development of HeartMate II® is thus praised as a desired improvement.

The implanted machine is connected to external parts of the HeartMate II® system with a so called 'percutaneous' cable – a plastic lead for power supply. 'Percutaneous', in medicine, means 'through

skin⁸ and is in case of a mechanical help heart implantation used to describe a non-invasive procedure where access to and from the inner organs⁹ is made by a needle puncture of the skin tissue. In the case of the HeartMate II® the plastic lead that connects the implanted pump with the external System Controller through this percutaneous skin perforation actually goes through the tissue of the abdominal wall. Hence, it is a tunnel that leads from the implanted pump to an always open sore on the patient's belly exposing him or her to risks of infection. Any bacteria that enter the lead and thus the patient's body are extremely dangerous. In fact, most deaths among Heartmate II® patients are caused by these kinds of infections.

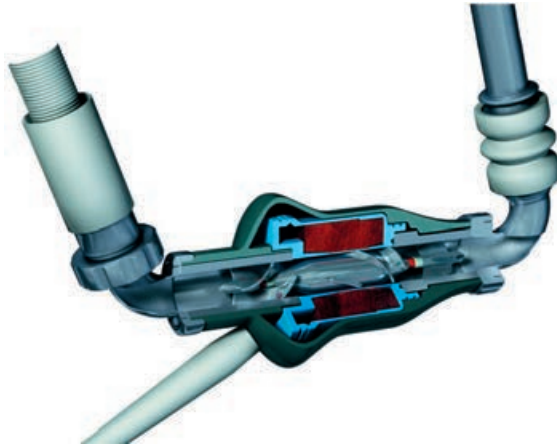


Figure 7: HeartMate II - Cutaway (Reprinted with the permission of Thoratec Corporation)

Finally, two rather large and heavy lithium batteries are worn in a holster or in a belly bag/waist pack. An additional set of batteries and battery clips are provided to the patient in order to prolong mobility without recharging the batteries. All of these components are mobile.

The system, as a whole, also includes a stationary Power Base Unit (PBU) with System Monitor and Display Module attached, and it is made somewhat mobile by a rather large and clumsy pushcart. This

⁸ Latin *per* = through and *cutis* = skin.

⁹ In this case between the mechanical help-heart and external power supply.

is the docking station for the patient at night – it is directly connected to the power supply in the wall – and for a long time was the only equipment for storage and recharging the batteries. Recent development has, however, resulted in a new portable Universal Battery Charger weighing 3.6 kilos and a Power Module that is only

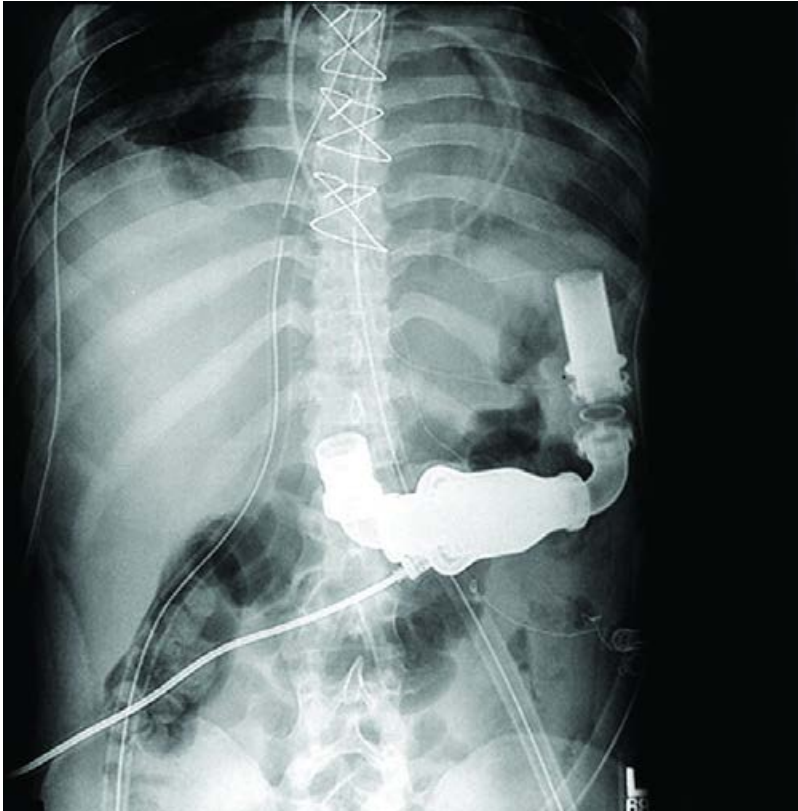


Figure 8: HeartMate - X-Ray (Reprinted with the permission of Thoratec Corporation)

one- third of the weight of the PBU. Pump speed can be adjusted in parameters of 200 rpm and can only be done on the System Monitor. This is also where the patient, the patient's relatives, and the medical staff can read and monitor the pump activity. The display panel shows: a) pump flow (indicated in liters per minute), b) pump speed

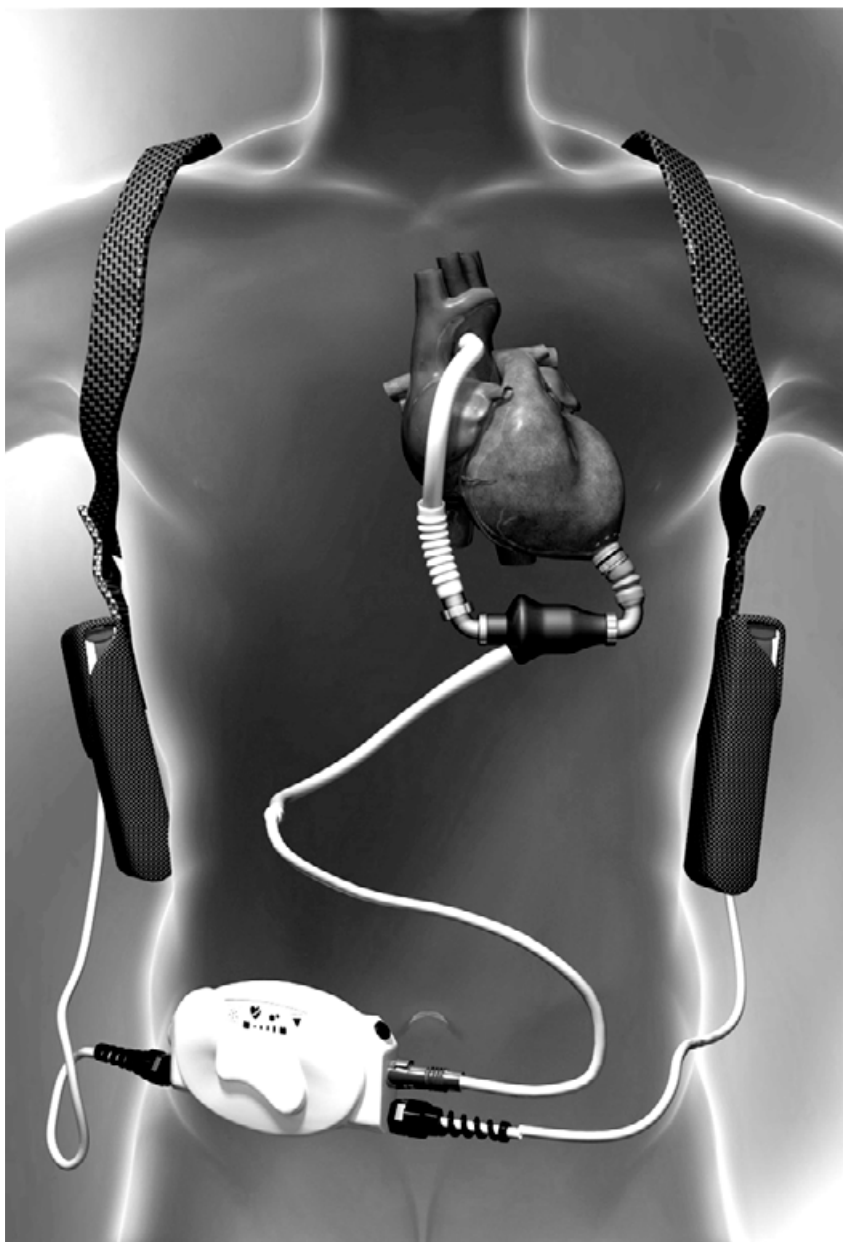


Figure 9: HeartMate II® with external equipment (Reprinted with the permission of Thoratec Corporation)

(indicated in revolutions per minute), c) pulse index (indicated as a measure of the relation between the preload of the left ventricle and the pump speed), and d) pump power, i.e. power consumption (indicated in wattage numbers). The pump speed, pump power, and left ventricular preload are the only exact values; pump flow is an estimated value based on the pump's power and speed, i.e. on algorithmic calculations of the relation between those two values.

The pump house weighs no more than 281.3 g and is 4.3 cm in diameter and 8.1 cm long. The entire device that is implanted inside the patient's body, i.e. the titanium pipe with the built-in impeller together with the inflow and outflow conduits and the percutaneous cable, weighs around 500 g. The System Controller is 17.8 cm long, 5.7 cm wide, 9.5 cm high and weighs 650 g. Batteries weigh 0.650 kg a piece and are 18.4 cm long, 6.1 cm wide, and 2.5 cm high and can last for up to 5 hours. The battery clip weighs 104 g and is 8 cm long, 3.2 cm wide, and 9.2 cm high. Furthermore, the patient is never to leave the PBU without an extra System Controller and a set of extra batteries and clips (depending on how long he or she plans to be away from the PBU). This amounts to nearly 5 kg of extra weight. As one of the patients expressed it "... this may not be much for a healthy person but for a person with a sick heart it's a whole lot of weight".

TECHNOLOGY OF HOPE

When all other treatments fail, the Cardio West artificial heart can save the sickest of the sick.

Dr. Jack Copeland, Chief, Cardiothoracic Surgery, UMC, Tucson
(SynCardia Systems 2006)

Never before have physicians had so many options to treat cardiovascular disease and new studies offer hope for future generations. Our pursuit of discovery will continue until the threat of cardiovascular disease is removed from all our lives.

Sincerely yours,

Denton A. Cooley, MD
(Texas-Heart-Institute 2008)

These quotations, accompanied by photos showing smiling and remarkably vigorous heart failure patients who now are alive thanks to the mechanical help-heart technology, present a rather beautiful and romantic scenario in various brochures, reports, and web-sites linked to the manufacturers and/or hospitals in which they are being



Figure 10: Photo of a HeartMate patient fly-fishing (Reprinted with the permission of Thoratec Corporation).

used. The persons featured in these stories are depicted as survivors, overtly glorified through the excellence of the life-saving cutting-edge technology. They are also portrayed in recognizable habitats – at home, in the garden, walking the streets, running down the jogging track, fly-fishing, training with a punching bag or being effective at work. They seem to enjoy the company of their relatives, friends, and colleagues. For the most part, the picture of their strength is far from modest. In the SynCardia 2007 Annual Report, one of the patients, an older man who survived the bridge-to-transplant therapy with an HAD implant for one year before he finally received a new donor



Figure 11: Photo of a CardioWest Total Artificial heart (TAH) and transplant survivor in a triumphant gesture (Courtesy: syncardia.com)

heart transplant, is even shown picking up his bicycle and elevating it above his head in a triumphant gesture. There, in an email sent to SynCardia, he tells the story of being physically fit with the artificial heart, feeling dignity, and enjoying relative independence. He also tells about managing to walk six km a day just a few months after the subsequent transplant, camping in a Winnebago, and riding a bicycle for 40 km.

I was able to leave the heart center clinic 5 weeks after my transplantation. In Munster I did my first bicycle tour since the transplant – 40 km. October 23, 2007 ... Physically I am doing better than I have in years; I find fun and enjoyment in my life. And all this largely thanks to a machine: **Cardio West Temporary Total Artificial Heart!**

(SynCardia Systems 2007: bold emphasis in original)

Stories like this are gripping. They tell of victory and they offer promises and hope to hundreds of thousands of heart failure patients around the globe.



Figure 12: Photo of a HeartMate patient riding a bike on a sunny day with her young daughter sitting in the back (Reprinted with the permission of Thoratec Corporation).



Figure 13: Photo of a HeartMate patient enjoying her time with her family (Reprinted with the permission of Thoratec Corporation).

The technological progress that made heart transplantation possible has led to conceptual, institutional and cultural changes. The body was suddenly just an assemblage of spare parts and the heart was no longer the definition of life but a replaceable pump (Nathoo 2007: 156). The ceased heartbeat no longer indicated death – life was now a cerebral thing. This gave birth to new practices which in turn required new conquests of the future – what is seen as the supply of replacement hearts has proved unable to match what is seen as the ever-growing demand of the replaceable hearts, and thus the ambition of making them began. At the same time, all of this was closely covered by the beam of media light with iconic depictions of



Figure 14: Photo of a CardioWest Total Artificial Heart (TAH) patient enjoying an in-hospital Halloween party costumed as "The Queen of Hearts" (Courtesy: syncardia.com).



Figure 15: Photo of CardioWest Total Artificial Heart patient working out and boxing at the hospital gym (Courtesy: syncardia.com).

pioneering surgeon-heroes in spite of the fact that the “... pioneering surgical procedures have had high initial mortality rates” (Nathoo 2007: 158).

The media paint striking pictures of medical-technological conquests through news with headlines such as “New Heart Pump

Can Save Many Lives”, “First to Implant the Wholly Mechanical Heart”, “Milestones”, “In Search of Antidote to Death”, “The Heart That Beats for the Future”, “Cardiac Surgical Trailblazer”, “Progress in Lund with New Heart Pump”, “A Citizen Saved by New Pump”, “Mechanical Heart is Saving Lives”, “Mechanical Heart Replaced the Patient’s Own Heart”. Occasional news of backfire and mishap such as “The First Person With Mechanical Heart Died” or “Artificial Heart Provides Hope and Disappointment” do also appear from time to time. Indeed, everybody seems to be a bit intimidated by it – but we seem also to find it extremely fascinating and promising. This might be the reason why the news reports of regress and mishap are largely outnumbered by those in praise of progress brought by medical technology. Numerous popular scientific channels raise a chorus of praise for the engineering minds behind the mechanical hearts.

It would be naive to think that technology can be properly studied apart from the people who make, use, and live it. The complexity of human dimensions of technology cannot be grasped by numbers, nor portrayed by diagrams alone. This is why I hold that any in-depth understanding of how we use technology and what it means to us requires an approach that would emphasize the daily work of technology, i.e. everyday practicalities where technology is used and talked about, contested and negotiated, manipulated and experienced, altered and adjusted to, managed and, ultimately, lived. What better place for such an enquiry than a high technology university hospital? Not only does such a place provide technology galore, but its entire structure is built upon and is highly dependent on the functioning of this high-tech grid. What’s more, the efficiency of technological practices in such a setting literally means the difference between life and death.

IV PREVIOUS RESEARCH – AN OVERVIEW

The aim of this study is to explore ethnographically the cultural aspects of mechanical help-heart treatment. To do so, I look into the intersection between: i) modern biomedical ways of dealing with life-threatening chronic illness; and ii) professional enactment of promises of medical technology in a context of its ever-increasing development. By investigating the cultural understandings of life-threatening illness and its technological remedy as they are being created *in situ* in clinical practices in a modern Swedish university hospital, I hope to develop a more complex and culturally informed model for understanding the relationship between humans and technology.

In the following, I will outline the current state of scientific knowledge concerning this subject in order to identify white spaces and knowledge gaps, as this study's motive and rationale. The first section, *Medical technology*, provides an overview of the broad contextual backdrop against which this study is seen. The second section, *Anthropology of life-saving heart technologies*, aims to synthesize the main currents in recent anthropological/ethnographical research on this subject. Finally, the third section, *Anthropology of liminality and chronic illness*, outlines the ways in which concept of liminality have been used in previous anthropological/ethnographical studies of severe chronic illness, in order to clarify the link between the previous research and my choice of theoretical framework, i.e. the healing ritual¹⁰.

MEDICAL TECHNOLOGY

The subject of 'medical technology' is multifaceted as it cuts across the boundaries between the social, the cultural and the corporeal. Its key elements differ depending on the contextual particularities of its deployment and also on the perspective from which it is being

¹⁰ Which will be explained in detail in CHAPTER THREE – THEORETICAL FRAMEWORK (pp 121).

observed. Juxtaposed with the subjects of 'life-threatening chronic illnesses' and 'clinical practice', it gains even more in qualitative richness and complexity. From what angle, then, should it be approached to suit the purposes of this study? Should close attention be paid to the role of medical technology regarding the incurability and uncertainty of chronic illness and the dynamics between patienthood, identity, and subjectivity related to it? Or is it all about hope and promises of life-extending medical technologies? Or about power and authority of political-economic structures, clinical evidence-making, and structures of private industries and social fabric? Then again, what about the human body? Or culture(s) of medicine? Or relationships between medical practice and medical science? Or...?

Given its distributed and equivocal nature, medical technology seems to stretch beyond being merely a central feature in modern medical care. It is fluid and difficult to define, intractably escaping identity, which makes it an exceptionally fertile ground for interdisciplinary investigations. Therefore, a proper overview of previous research is required for a wide range of bits and pieces from several research areas and scientific disciplines to be identified, clustered, placed in order of relevance, and considered accordingly. My roots, however, are in anthropology and cultural studies which will remain the primary outlook here. Ultimately, the purpose of this overview is to identify a scientific environment that is relevant to this study, and within which this study can be positioned.

Usually, new cutting-edge medical technology is assessed by various forms of quantitative measurement. Besides common initial focus on technical and physiological particularities along with the therapeutic and/or life-saving efficiency of certain technological innovation these may, on one hand, involve the measuring of the characteristics of innovation process for certain technology. Examples of this are: 1) the extent of the spread of innovation among potential adopters, 2) the quantity of innovation used (how much and how often), 3) the speed of the process from one particular point to

another, and 4) probability of the innovation actually coming into and remaining in use (Roback 2006). On the other hand there are various quantitative analyses of survival rates and cost-benefit ratios of particular technologies, the main purpose of which is "... to tell us which technologies are worth public investment", (Plough 1986: 5). There are also vast numbers of attempts to grasp the well-being of patients treated with new technology, by utilization of quantitative instruments for measurement of life-quality such as Quality of Life Index (QLI). Still, numbers and diagrams have thus far failed to provide us with any deeper insight into the more complex and often conflicting dimensions of using, assimilating to, and ultimately living with high-end technology, especially when lives are depending on it.

One scientific area concerned with relationships between new scientific and technological innovations, society, and the body of the individual which by now it constitutes a recognized body of knowledge of social science is covered mostly by the umbrella of what is usually referred to as *Science and Technology Studies* (STS)¹¹. A significant part of this pool of research is devoted to questions about medical technologies used to maintain, assist, and substitute for parts of the human body. Perhaps one of the most central issues in this tradition has revolved around the "... cultural significance of ... technological innovation in redefining the meaning of medicine and health", (Brown and Webster 2004: 1). New medical technologies are recognized as an expression of what might be viewed as contradictive combination of concurrent *reproduction* and *deconstruction* of relationship between body, medicine and technology in which they provide hope and salvation on the one hand but also risk and uncertainty on the other (Brown and Webster 2004: 179). Here, new medical technology is seen as embedded in a wider sociocultural context, intimately connected to "the manufacture and circulation of hopes and promises", (Brown and Webster 2004: 180). The role that the Medical-Industrial Complex (MIC) plays here should by no means be

¹¹ STS is an interdisciplinary specialty that cuts across sociology, anthropology, ethnology, history, gender studies, feminist and culture studies, etc.

overlooked. "[It is a] multibillion dollar industry producing thousands of products ... The demand seems insatiable. We have come to expect a steady stream of new 'miracles'", (Bartlett Foote 1992: 4).

Feminist and cultural studies constitute yet another closely related intellectual current, mainly concerned with the question of conceptual boundary transgression as a result of the integration of new technologies and human bodies. Donna Haraway, one of the front figures, used and developed the concept of 'cyborg' as a concrete merger of science fiction and social reality. In this merger, what we used to perceive as the boundary between science fiction and social reality is turning into a mere false impression, "Our machines are disturbingly lively, and we ourselves frighteningly inert" (1991).

Feminist philosopher and cultural studies scholar Roisi Braidotti has more recently warned about: "... enthralling promises of possible re-embodiments and actualized differences [and multiple] virtual possibilities", (2006: 204). Braidotti describes Haraway's cyborg as an alternatively structured 'other' that enables the (re)conception of posthuman and post-anthropocentric contemporary world where the various genres of science fiction (such as science fiction horror and cyber punk) appear to be the best "... fitting cultural illustrations of the changes and transformations that are taking place in the forms of relations available in our post-human present. Low cultural genres, like science fiction, are ... a more accurate and honest depiction of contemporary culture than other, more self-consciously 'representational' genres" (2006: 203). Drawing on Haraway, a scientific current called *cyborg anthropology* (Downey, et al. 1995) engages in the ways machine bodied hybrids create new social and cultural forms as well as new modes of agency and existence. The cyborgs are, thus, but a cultural expression and quintessence of science, technology and medicine embodying the future promises through biomedical enactments of technological innovations (Casper and Koenig 1996; Downey, et al. 1995)

A considerable number of scholars interested in the social and cultural impact of changes in biomedicine and biotechnology on our

understanding of human life itself, have carried on the Foucauldian heritage and his ideas on *biopower* and *biopolitics* (2004[1976]). These ideas revolve around the complex relations between power, knowledge, and normative discourse of ‘biological’ sciences and their ‘objectivizing’ of the living, thinking, and feeling subjects through what Foucault calls ‘dividing practices’, common in mental institutions, prisons and hospitals (Foucault 1982; Foucault 2003[1975]; 2006[1972]; 2006[1963]; Kaufman and Morgan 2005; Moreira and Palladino 2005; Penley, et al. 1990; Rabinow and Rose 2006; Raman and Tutton 2010; Rose 2001; Rose 2009; Rose 2007; Whyte 2009). Main findings almost univocally depict the web of relations wherein the life world of the patients is continually being curbed by the highly technological and reductionist power-knowledge of biomedicine, which in turn is intimately entangled in the wider web of global political-economical forces. Thus, through usage of concepts of biopower and biopolitics a new, and closely related, pair of theoretical concepts has been developed: *biosociality* and *biological citizenship* (Petryna 2002; Petryna 2004; Rabinow 2008; Rose and Novas 2005). These concepts were then used to describe the emergence of new social practices and new forms of identity in the wake of the reign of biomedicine and technoscience where biopolitics and biopower have shaped the ways in which individuals view themselves and their relation with others – they understand their place in society in biological terms and have developed strategies of utilizing their new status positions to manage their existence in that society.

The focus that biomedical discourse surrounding transplantation places on social values of ‘altruism’ (of donors) and ‘individual rights’ (of recipients) was described by Joralemon as “... the ideological equivalent of immunosuppressant drugs, designed to inhibit cultural rejection of transplantation and its view of the body” (1995). A similar understanding was echoed almost a decade later (through a similar metaphor of cultural immunosuppressants) by STS and culture studies scholar Susan Merrill Squier in her book *Liminal lives: imagining*

the human at the frontiers of biomedicine (2004). Instead of strategic usage of emotionally charged concepts of altruism and individual rights in biomedical transplantation discourse, Squier points out 'science fiction', not merely as a mirror of contemporary culture as Haraway and Braidotti would have it, but as a kind of ideological immunosuppressant for society, enabling eventual public acceptance of new high-tech biomedical practices and also, in a sense, announcing the shape of things to come (Ibid: 200).

ANTHROPOLOGY OF HEART-RELATED LIFE-SAVING TECHNOLOGIES

In the following I will outline some of the main findings in anthropology of life-saving and heart-related medical technologies. These findings are presented in five clusters, based on the discoveries that most frequently occur in the body of research that has been covered:

1. Global technology in culturally specific places
2. Technology, industry and consumerism
3. Technology as carrier of normative models
4. Technology and transformed sense of the self
5. Technology and 'margins of life'

Not only are these themes in no way as isolated as this static structural outline might suggest, more often than not they overlap, coexist and imply each other. I will try to preserve these correlations, dynamics and fluidity throughout this presentation, while still trying to use this thematic outline to provide a more or less comprehensible overview.

Global technology in culturally specific places

In an attempt to synthesize and comment on a handful of articles addressing the theme of organ transplantation featured in a special issue of *Medical Anthropology Quarterly*, anthropologists Barbara Koenig and Linda Hogle stress the importance of exploring culturally

specific ways of understanding and enacting what appears as standard, homogenous medical practice (Koenig and Hogle 1995). A year later, in order to provide a more nuanced cultural portrait of organ transplantation as a comparative contrast/complement to the already available accounts from the United States (Fox and Swazey 1974; 1992; Joralemon 1995; Lock and Honde 1990; Sharp 1995) Hogle offers a 'report' based on 16 months of impressive long multi-sited fieldwork conducted at university clinics, community hospitals, public gatherings, and policy meetings in 12 German cities (Hogle 1996). Here she observed and interviewed transplant 'coordinators', transplant surgeons, intensive care and surgical nurses, pathologists, researchers, members of groups working against the 'brain-death' as main criterion in determination of death, tissue commodification groups, lawyers, policymakers, administrators of tissue banks and members of organizations supporting organ donation (Hogle 1996). Hogle's main point here is that this global biomedical practice looks different in different cultural contexts. While the focus on technological progress in the US, especially on emerging profitable techniques developed for use in dead bodies, renders commodification of body parts relatively unproblematic, the German sociocultural environment presents different conditions which make these practices highly problematic (Ibid).

Anthropologist Margaret Lock, through comparison of North America and Japan based on the historic materials in combination with medical, philosophical and media publications on organ transplantation, also emphasized the culturally different ways of ascribing moral value to the demands of organ transplantation practices (1996). The relatively easy establishment of a new cultural definition of end of life in North America, i.e. 'brain death', rests on culturally accepted measurable scientific criteria. In contrast, she claims, death in Japan is interpreted as a process and also as a social and non-individual event whereby the idea of scientifically defined death as a measurable point in time was met with skepticism and resistance, both by the public and by many clinicians (Ibid). Lock

takes the same stand a year later in a similar article adding that the revised death criteria – from cessation of heart beat to irreparably damaged brain – is a ricochet of highly questionable utilitarian interests of transplant world. “Culture has intruded into nature – into dying – in the guise of science”, she concludes. At the same time she points out that the comparison between North America and Japan demonstrates how this deeply penetrating intrusion, even in places such as North America where it is broadly accepted, in fact is permeated with uncertainty and lack of consensus among the experts (1998: 429).

In her book *Twice Dead* (2002), Lock gives a more detailed analysis of the ways in which heart transplantation is having a particular cultural impact on the way death is understood locally. Previously diverse and culturally specific understandings are being contested through routinized new uniform medical practices where new technologies are being used. A couple of years later, in an attempt to provide a broader comparative picture of transplantation practice, Lock, together with her anthropologist colleague Crowley-Matoka, points out that, in spite of being subject to local social and cultural influence where it is always contested by the local understandings of life and death, self and other, and gift and commodity, this biomedical practice is nonetheless a global phenomenon where “... cultural meanings and social organization that shape organ donation and transplantation in any one place may be both profoundly connected to and enormously consequential for the existence of this biotechnology elsewhere” (2006: 179). The point she makes is that transplantation should by no means be understood as a globally homogeneous practice grounded in mankind’s uniform understanding of life and death. Then again, neither should any of the locally performed transplantations be viewed as completely isolated from other transplantations performed elsewhere. Or in the words of Nigel Thrift, in his commentary on Donna Haraway’s renown ‘Manifesto’, such “dynamic technologies of propensity” are, each time they are performed, immediately also: “... tagged and integrated into

metasystems which are part and parcel of those things' existence" (2006: 191). In similar fashion, Lock's research demonstrates that particular cultural variations of the ways these practices are viewed and performed bring more nuance and dynamics to an already widely spread biomedical practice and to biomedicine at large, i.e. understood as a dominant global system of dealing with illness. This allows us to take a somewhat less keen stand towards the newly emerging and by inertia readily acceptable biotechnical facts (see also Lock 2004).

Technology, industry and consumerism

Furthermore, while praising the contribution of a critical perspective of medical anthropology as it manages, through ethnographic evidence, to reveal "... that biomedical claims of Truths are not accepted as *the* representation of reality" (Koenig and Hogle 1995, italics in original) the authors urge that transplantation practices need to be analyzed in a broader macro perspective in an attempt to examine "who profits from and who is benefited by the transplant industry". They conclude that "... there is little doubt that the 'demand' for transplant is created by the commercially attractive promise of yet another technique for pushing back the boundary between life and death" (Ibid: 395, 396).

In her more recent work, Hogle focuses on what she calls 'enhancement technologies', referring to biomedical technological ability to augment bodily forms and functions (Hogle 2005). Along with this biotechnical alteration of biology, she argues, social conditions and cultural expectations are also being altered. These technologies aim to improve human characteristics with respect to their aesthetics of appearance and also to their mental and/or physical functioning. Her focus, however, remains on the kinds of enhancements that are beyond what is considered 'normal' or therapeutically necessary for life and well-being, such as cosmetic surgery and neurological and genetic enhancements. In general, Hogle is critical of the usage of these technologies as means of modifying

our bodily forms and functions because, as she argues, they turn our bodies into “the objects of improvement work [with] profound effects on sociality and subjectivity” (Hogle 2005).

Hogle’s main argument is that “... marketing and cultural expectations of how the body should perform are central to shaping the relationship of bodies and technologies” (2005: 703). Hence, she concludes that “enhancements are upgrades” and as such they justify and uphold the consumerism and capitalist market of goods (new medical technology) and services (health care) and its technoculture of exchange-oriented research and development (Ibid: 703).

Technology as carrier of normative models

A couple of years later, in examining the ways in which mechanical hearts are visually presented by bioengineers (as drawings, images, sculptures etc), Sharp reveals the moral keystones of the embodied aesthetics of the standardized human body under the influence of bioscientific imagination – a strong, erect, potent, well-toned, fit, young male body, perfected by the array of polymer tubes, titanium casings and electrical cords (Sharp 2011). Through these images, the notions of ‘robust’, ‘hard’ and ‘strong’ are used as markers of desired bodily value in contrast to those of ‘gentle’, ‘soft’ and ‘weak’ which are treated by the bioengineers as undesired qualities characteristic of troublesome female bodies. Thus, these mechanical innovations carry the normative models of an ideal masculinity the main quality of which lies in their potential to *perfect* the fallible and frail qualities of human corporeality. Hence, the bioengineers reach beyond the initial moral imperative that propels their work, namely the efforts to eliminate the organ scarcity, and engage in perfecting, i.e. upgrading the human body in harmony with the ideal of their scientific imagination (Ibid). In this study Sharp focuses exclusively on bioengineers working with mechanical heart devices, leaving the patients and physicians out of the picture.

Sharp has elsewhere also focused on the issue of commodification inherent to emergent biotechnologies such as organ

transplantation, reproductive technologies, cosmetic and transsexual surgeries, genetics, and immunology (Sharp 2000). Anthropologist Scheper-Hughes has also discussed commodification of body parts in connection with capitalist expansion, arguing that behind all the talk about love, pleasure, altruism and kindness associated with organ transplantation practices there is a dark side of economic exchanges and trafficking (2001a; 2001b). This is one of the examples where a certain kind of technologically imposed normative model (in this case commodification of body parts) is intimately connected to the Medical-Industrial Complex (MIC) and consumerism of the contemporary Western world.

Other normative models involve a war-like scenario where life is waging war on death. Drawing from the STS Latourian concept of *hybrid* (as a combination of natural and sociocultural subjects/objects) and from Haraway's idea of cyborg (as a technologized body), anthropologist Margaret Lock points out that the increasing implementation of invasive biotechnologies, such as organ transplantation, rests on and reinforces the currently dominant Western cultural normative model: "Striving for immortality is unquestionably a laudable goal, just as resignation to death is a sign of weakness and defeat" (1995: 391). Elsewhere she points out that "The medical world ... has reinforced a vision of death as a scandal, a failure. This is equally true for the profession in the United States, Canada, Japan, and elsewhere. Death is cast as the archenemy ... a condition to be perpetually postponed. Transplant technology ... opens the door to technological transcendence of death – a chance to make meaning out of a 'bad' death" (2002: 366).

In contrast (or as a complement) to Hogle's call for an anthropological macro perspective on these practices, Lock stresses that the only way to understand the collective cultural pursuit of indefinitely prolonged life is by focusing on the ways in which these practices are "... enacted in the everyday lives of those most deeply involved with the new technologies" (Ibid: 393). Lock's main point is that transplantation is propelled by the modern quest for immortality,

understood as the ultimate victory over the forces of nature (Ibid). Or in a word, this is the normative model that is being ‘enacted in the everyday lives’ of patients and medical professionals.

Anthropologists Sharon Kaufman and Lakshmi Fjord use the example of liver transplantation in US to emphasize the emergence of what they call *ethicality*, i.e. “... the form of governance in which scientific evidence, Medicare policy, and clinical knowledge and practice organize, first, what becomes ‘thinkable’ as the best medicine, and second, how that kind of understanding shapes a telos of living” (2011: 209). Although this particular study uses the example of liver transplantation, the authors address the issue of end-stage chronic illness and life-extending technologies which are rather analogous to heart transplantation practices. Moreover, Kaufman has addressed the issue of heart-related medical technologies in her other publications¹² (cf. Kaufman, et al. 2011; and also Kaufman 2009; 2010). Clinical treatments of life-threatening diseases, the authors argue, link powerful ideas of biomedical progress to a patient’s life course and, justified by hope, enact a “colonization of future” revealing the “anticipatory nature of contemporary life” (Kaufman and Fjord 2011: 210). The authors also stress that “future is brought into the present” as it is being forecasted through the diagnostic prognosis, risk assessment and construction of biotechnical promise (Ibid: 210).

Furthermore, Kaufman and Fjord emphasize that there are structures of private industry, science, and evidence making, which place high moral value on technological interventions and on rational-technical ways of knowing in clinical practice. Again, this shows how strong the links are between MIC and embodiment of its normative models. Hence any questions about looming death and ‘the right thing to do’ are already answered by the authority of biomedical *ethicality* which thereby is placing the responsibility of choosing this right thing on health care consumers (Ibid: 211). Ultimately, this ethicality arises in: i) medical knowledge, ii) multiple imperatives to prolong life inherent to that knowledge, iii) payment policies, and iv)

¹² Which are also addressed in this review.

routinizations of clinical practices such as organ transplantation. Being such a complex and powerful phenomenon, ethicality shapes cultural understandings of the meaning of life and death, morally 'right' choices for individual conduct, and also the structure and dynamics of US economy.

This biotechnical construction and deployment of 'hope' is inherent, according to Kaufman, in all biomedical practices that deal with bridging the gap between end-of-life situation caused by lethal chronic illness and 'heroic' new life through life-extension: "... hope is always embodied in heroic interventions" (2009: 321). Ultimately, in a review of recent anthropological studies on 'beginnings and ends of life', Kaufman, together with anthropologist Lynn M. Morgan, concludes that recent ethnographic findings mirror the classical anthropological accounts of 'vital connections between the living and the dead': "The disposition and memorialization of the dead profoundly inform the social identity of the living [...] death is an initiation into an afterlife, a rebirth" (2005: 323) recognizing the problems that contemporary biomedical life-extending technologies pose to these matters.

Transplantation practice has had significant influence on various local cultural understandings wherever it has been introduced. Besides the already-mentioned cultural categories of life/death, self/other, gift/commodity it was also said to stimulate the individual appetite for 'continuation' so as to make her fit into the frames of normality posed by current Western society: "If future appropriations are put at risk by a [...] fragile body, there is a world of potential *biotransformations* available for reengineering the body", writes Maynard. He emphasizes that transplantation "can help sustain the biological continuity of individual narrative" due to its influence as a "*new form of embodiment*" that is brought to the fore by recent developments within the field of medical technology and by doing so reinstall the individual "within a [mainstream] social narrative of the normal", (Maynard 2006: 227, my emphasis).

Technology and transformed sense of the self

Not only is end-stage heart failure a life threatening chronic illness, it is a condition of the dying. In chronic illness in general, patients experience 'loss of self', biographical disruption, and develop various strategies of making sense of their lives with chronic illness (Charmaz 1999; Hydén 1997; Murphy 1987; Pierret 2003; Shildrick 2010; Toombs 1993; Toombs 1995). The research stresses that chronically ill people might reconfigure the meaning of conceptions such as time (developing the sense of extended present in times of uncertain future, or measuring time in *before* and *after* the first encounter with diagnosis of their chronic illness) and space (the sense of space gets to a greater extent confined and limited as their bodies lose the mobility they once enjoyed). Consequently, all these altered conceptions affect patients' sense of self. A branch of anthropological scholars has been interested in the ways in which a patient's sense of self is influenced by treatment with heart-related life-saving biotechnologies – a field of human existence that is particularly interesting for anthropologists as the illness in question is so severe while its treatment is so 'heroic'.

Picking up on the earlier-mentioned issue of conceptual boundary transgression, a number of researchers show how the possibilities inherent to organ transplantation technology – of manipulation of nature/culture, self/body, and self/other dichotomies – affect the experience of the chronically ill. Research stresses that the practices of organ transplantation seem to imply embodiment of imagined *other* through integration of harvested healthy organ into the sick body (Koenig and Hogle 1995; Lock 1998; Sharp 1995). This is where the dichotomy between self/other and also between gift/commodity gets contested.

Based on exploration of professional writings and data generated from ethnographic research on heart transplantation in United States, anthropologist Lesley Sharp emphasizes the contradictory logics of transplantation practice, as it is grounded in competing needs to both personalize and to objectify organs and bodies. Thus, the organ recipients rebuild their sense of self in a transformative process

through which their identities emerge as fictionalized and extended biographies (Sharp 1995). In her more recent work Sharp addresses the emergent biotechnical research areas that compete with organ transplantation – xenotransplantation and implantation of mechanical hearts (Sharp 2007). Here, she emphasizes that, when asked about animal and mechanical replacement options, patients seem to favor the latter. The reason for this is that the mechanical alternatives are not perceived as a threat to their identity – they are neutral and, in contrast to pig or baboon hearts, contain no association to an ‘other’.

Technology of ‘margins of life’

The notion of ‘liminality’, which in the context of biomedical life-extending technologies can be understood as “betweenness – the liminal state of being not dead, ‘not alive’, yet ‘like a corpse’”¹³ (Kaufman and Morgan: 324), was originally coined by van Gennep (1960[1908]) and developed by Turner (1997[1969]). According to Kaufman and Morgan, the concept of liminality has influenced a significant array of anthropological writing on ‘margins of life’ (Kaufman and Morgan 2005: 332). However, the authors add, this was the case at least “... until Foucault’s work gained prominence” (Ibid: 332). The collective body of anthropological research on this theme shows that, in tact with development and increasing implementation of life-extending biomedical techniques, ill people are not merely caught in temporary in-betweenness but find themselves suspended in a complex web of “... new forms of life, liminality, knowledge and social organization” (Ibid: 333). Although I do agree that the influence of Foucauldian concepts of biopower and normative construction of compliant subjectivities on current anthropological research on body, medicine and technology cannot, and should not, be overlooked, I would not discard Turner’s concept of liminality as being merely a structural-functionalist remnant, forced to recoil before the advance of some more hip and up-to-date critical theory. Instead, I would say that the array of new analytical tools, the

¹³ For more detailed discussion of the concept of liminality see pp 145.

root of which is to be found in the work of Foucault (biopower, biopolitics, biosociality, citizenship, discipline, subjectivity, governmentality, appropriation etc) is a result of new social and cultural circumstances and as such render the ‘betweenness’ of a treated person analytically more accessible. Or in a word, the observed phenomena gains harmonic richness. In fact, although new circumstances and new practices bring about new cultural forms and new modes of existence, the lives of the saved patients are still the same ones that they’ve had before. Their biographies are *extended*, as Sharp described it (1995), not replaced or created anew. Only the direction and mode of their biographies is new. Although heavily altered and subjugated, the saved patients find themselves still along the same biographical continuity – the difference being that it is biomechanically perpetuated. In spite of the fact that their ‘biological’ lives are abruptly transformed into ‘biotechnical’ ones, the rebirth is still just symbolical. In the mean time, their liminality is, instead of being temporary, transformed into a very concrete and quite troublesome one. Therefore, I argue that Turner’s concept of liminality is still a rather adequate and potent analytical tool.

ANTHROPOLOGY OF LIMINALITY AND CHRONIC ILLNESS

The concept of liminality is not new to the ethnographical studies of chronic illness. One of the first to use the concept of liminality in order to explain the *at-the-margin* social situation of the chronically ill was anthropologist Robert M. Murphy, who focused on paraplegics and quadriplegics in the New York metropolitan area (Murphy, et al. 1988). Murphy’s accounts are at least partially *autoethnographical* as he suffered from a tumor in the spinal cord that slowly progressed into quadriplegia (Murphy 1987). Tracey Skillington makes use of the concept of liminality in her study of a holiday camp for seriously ill children as a contemporary equivalence of rites of passage¹⁴ with evidently beneficial effects on these children (2009). Little Miles and

¹⁴ See Ritual Theory section in CHAPTER THREE – THEORETICAL FRAMEWORK (pp 122).

colleagues use liminality to describe the acute and sustained liminality of the experience of cancer (Little, et al. 1998). Jeffrey Willet and Mary Jo Deegan describe the situation of disabled as permanent liminality and blame the structure of 'hypermodern' society for being obstructive to the reintegration of disabled members "... because it fails to provide them with stable, socially valued roles" (2001: 137). Honkasalo makes use of the concept of liminality to understand the paradox of permanent transience in "... ambiguity surrounding the identity formation of people in chronic pain" (2001: 340-41). Helen Allan describes experiences of infertile British women as occupying space of liminality in society and how fertility clinics provide a place of tolerance and alleviation of social isolation as long as the treatments are successful. When assisted reproductive techniques do not lead to conception, however, the sense of isolation and ambiguity is amplified and liminality is made permanent (Allan 2007).

Temporality of illness seems to be central here as the majority of authors are apparently intrigued by the kind of liminality that provides no exit. With this open-ended character of liminality, and the 'social invisibility' and ambiguity so characteristic of it, the illness experience "takes on a darker view" as Charmaz stresses in her critique of Murphy's *autoethnographic* approach (2006: 398). Nevertheless, her own notion of 'self on hold' as the main property of the experience of chronic illness is in no way less dark than Murphy's use of liminality, as it is marked by 'dreaded future', 'agonized waiting' and an 'unsettled and undetermined' present (Charmaz 1991: 33). This temporal vacuum in chronic illness experience is also addressed by philosopher Toombs as she writes about the paradox of being "effectively confined to the present" at the same time as the present is lost: "The actual present is forfeited and transposed into an imagined future" (1993: 225).

Although the issue of permanent liminality in chronic illness has been addressed by many, contemporary research on modern clinical treatments of chronic illnesses seems to lack detailed accounts of the institutionalized practices through which not only permanent

liminality but liminality of facing the constant threat of death is brought about, and also of circumstances ensuring its continuation through life-extending technologies.

Contemporary clinical practices are believed to be evidence-based, which means that they are supported by scientific knowledge. However, this knowledge is at all times permeated by gaps of uncertainty – domains of human existence that are just beyond the reach of formal biomedical knowledge. At the same time, ‘curing’ has been described as an ”... act of treating successfully a specific condition” while ‘healing’ refers to ”... the whole person or the whole body seen as an integrated system with both physical and spiritual components” (Strathern and Stewart 1999: 7). In other words, curing is understood as the treatment of specific conditions seen as diseases and healing as restoring wellness to the body and a person as a whole. It is nowadays nothing of a novelty that biomedicine deals mainly with curing¹⁵, and not healing, while other medical systems¹⁶ deal with healing that either encompasses or stands outside of curing. The biomedical ‘curative’ approach is generally criticized for its insufficiency and is also said to be in need of a more holistic view of health and illness (Strathern and Stewart 1999). In light of this, I am interested in examining the strategies that medical professionals and patients develop in order to manage the elements of clinical practice that falls beyond reach of formal biomedical knowledge when actual human lives are at stake. I hold that a thorough analysis of these clinical practices as rituals will help identify underlying cultural forces at work, which will hopefully provide us with the kind of knowledge that right now is either completely absent or is at least not acknowledged and established, but which nonetheless seem necessary if we wish to make any serious estimation of how these challenges can be avoided. Not only do I adopt Turner’s concept of liminality as a theoretical framework to structure and clarify my data, but I also look

¹⁵ With exception of biomedical task to reduce pain and suffering.

¹⁶ Which, in the world of biomedicine, are classified either as alternative or as complementary medicine.

at the contemporary clinical practices of implantation of mechanical help-hearts *as* rituals. In light of this perspective I hope to come closer to understanding the social and cultural aspects of these late modern versions of traditional healing rituals.

SUMMARY

Research on medical technology, society, and the body seems short of extensive ethnographic accounts of the treatment of end-stage heart failure in a high-tech clinical setting. As mechanical hearts are being implanted inside human bodies we can no longer talk solely about reengineering the person with a disabled body back into “a [mainstream] social narrative of the normal” (Maynard 2006: 227) through artificial limbs and joints, or adjusting the people to the current ideals of beauty and normalcy through cosmetic surgical maintenance. The advance of medical technology is penetrating yet deeper into the human body, conquering some of its most symbolically loaded and significant parts. The heart is now technologized and disembodied. No longer is it merely replaced by the heart of other human but by a machine. Embedded in broader context of the ways in which developed Western countries are attracted to ideas of ‘growth’, ‘progress’ and ‘achievement’, the notion of ‘future appropriations’, addressed earlier (pp 45, 51), appears as a key objective and the foundation on which the late modern Western world seem to rest. It is both targeted as, and acquired through, the practices and technologies that seek to secure societal and personal progress and continuity. As was the case with organ transplantation, implantation of mechanical help-hearts is developed and used to defy finitude – to cut our way deeper into the future and also to protect these steps forward from any potential threats. At the same time, this progress into the future is simultaneously taking place on two different levels of abstraction: a) as a concrete personal journey into the future through a technologically extended biography, and b) as a part of a large-scale biotechnological colonization of the future. Yet there seems to be one essential qualitative difference between organ

transplantation and mechanical organ implantation. While organ transplantation implies embodiment of an imagined *other* through integration of harvested healthy organs into the sick body (Koenig and Hogle 1995; Lock 1998; Sharp 1995), this category appears, at first, to remain empty and enigmatic in the practices of implanting the machines. Sharp, for instance, describes how patients perceive mechanical hearts as neutral and consolingly vacant of an intruding 'subject' (the mind, ego, or agent of whatever sort that sustains or assumes the form of thought or consciousness – even that of a beast). Still, she leaves the category of implanted mechanical hearts completely vacant, avoiding the question of whether they may carry any other meaning whatsoever that might be of significance for anthropological curiosity and, if so, how we can learn more about them (Sharp 2007). In implanting the machine, then, what is being embodied? There is no concrete *other*, no donor, to be identified. Besides being perceived as life-savers, what other particular cultural meanings are these machines and the very process of their implementation attributed with?

Further, Sharp gives a very interesting account of bioengineers 'scientific imaginary'. Still, the question of what happens with their scientific imagination in the context of its realization as the mechanical hearts are being implanted in the bodies of dying patients still remains to be answered. Is their imagination of the potent, fit, young male body reproduced and transferred along the chain of actors? Or is it altered? If so, how? In short, what do mechanical hearts mean to medical professionals who are implanting them into the bodies of their dying patients? What do they mean to patients whose lives are depending on them? In what ways do these enactments of scientific imagination through routinized clinical practice influence the involved actors' understandings of deadly chronic illnesses and biotechnical solutions on the one hand, and also of their sense of self and their being in the world on the other? Ultimately, what kind of normativity is being embodied through enactment of this scientific imagination? Hogle's take on

‘enhancement technologies’ as ‘upgrades’ also bears a strong resemblance to Sharp’s account of bioengineers’ attempts to perfect the frail and fallible human body in accordance with the ideal image of the body ‘proper’ generated in their scientific imaginaries. The question of whether such a biotechnical ideal of the human body also influences the practice of clinical implantation of mechanical hearts, and thereby also the people whose lives are depending on them, still remains. In addition to extending lives, could these practices also represent an upgrade of our physical selves in accordance with the overall societal striving for continuity and progress, future achievements, i.e. the attempts of the modern Western world to colonize the future?

Kaufman and Fjord describe how the future is being brought into the present through the process of risk analysis. With regard to my ethnographic evidence, however, I would like to extend this argument to include the corporeal incarnation of future as its potency is being implanted into the actual bodies of the sick. Therefore, while patients make a perfect training ground for biotechnical testing the survivors serve as walking monuments of biotechnical effectiveness. Similar to the ways in which “... disposition and memorialization of the dead inform the social identity of the living” (Kaufman and Morgan 2005: 323) this role has in the context of emerging biotechnical clinical practices been given to the survivors as living monuments of biomedical success, carrying the promise and hope inherent in the technology that saved their lives. On the other hand, those who die trying – the non-survivors – are excluded from the picture altogether.

Some of the recent anthropological focus seeks to understand the “anticipation of death [and] the cultural forms that constitute the dying person” (Kaufman and Morgan 2005: 324). My research points in the direction of biotechnologically empowered anticipation of life and the cultural forms (amongst which also the styles of using and talking about the life-saving technologies) that constitute the living person. Kaufman and Morgan also conclude that a similar shift is

indeed taking place among the contemporary anthropologists as they seem to focus on these new forms at the margins of life (Ibid).

V

AIMS AND QUESTIONS

AIMS

The scope of anthropological enquiry is astonishing and entails “... literally anything from lemur feet to shadow plays ...”, and it has been referred to as: “*the dilettante’s discipline*”, (Rabinow 2007[1977]: 3, my emphasis). Even when a young anthropologist is very well-prepared for fieldwork, equipped with essential curiosity and a nice set of fair questions, it seems as if this disciplinary heritage of the value of detailed context, thick description, broad perspectives and, above all, the webs of significance wherein particularities lie embedded, always tags along and tugs one back from zoom in to zoom out.

As I went from gathering to analyzing data, however, the initial flood of my broad intentions has dwindled to a trickle of somewhat more specific questions. Although, as easy as this might seem, I must confess that the broad intentions still haunt me and remain an obstacle to whetting my inquisitiveness into razor-sharp questions. Of course, in anthropology, this is something that takes time and fine tuning. Research slowly surfaces through fieldwork and also through subsequent scrutinizing and analyzing the field notes, memories, and insights. Moreover, it is finally tweaked through writing. Still, the analysis and writing are, oddly enough, guided and shaped by the very questions they are supposed to answer. The trickle is violated by the same old flood over and over again. Looking at my field notes I recall the time I spent in the hospital evoking the experiences of the fieldwork, the people I met and rooms and hallways I roamed, to reveal the details of how clinical rituals of mechanical help-heart treatment were performed.

I look at the people whose lives depend on the implantation of mechanical devices. And yet, as I look at them through the lens of

practice, my focus is not primarily phenomenological but rather cultural and praxiographical¹⁷. This means that my aim is to ethnographically explore the cultural aspects of mechanical help-heart treatment as a modern biomedical healing ritual. I view these rituals primarily as cultural processes through which deaths are avoided and lives are saved. Furthermore, I treat these processes as communicative, expressing the ideological world in which they are rooted and which they help reinforce and uphold. These practices are built upon the use of various high-tech apparatuses and techniques on which they are heavily dependent and are, as such, entangled in the global nexus of technology research and development and in rapidly growing transnational markets for this technology¹⁸. It has been argued that "... biotechnology has come to take the place of rituals, spells, and prayers [and] has now simply made possible processes that people have desired and magically simulated or earnestly prayed for in the past, and still do, in all parts of the world" (Strathern and Stewart 1999: 167). Therefore, it is just as important to understand the *in situ* details of these practices as it is to put them in the larger context within which they operate. By simultaneously examining them as locally performed rituals and as a part of the global biotechnical nexus, I aim to explore, and also to demonstrate through ethnographic examples, how local claims of disease and health are refracted through ritualized institutional biomedical practices. I will also examine how the socio-political contexts in which the biomedical knowledge is made can influence particular courses of health, illness,

¹⁷ Although this approach is slightly adjusted at the final stage of the research where my focus on practice increasingly includes patients' own accounts of their post-treatment life (for more information see CHAPTER TWO – METHOD, pp 61).

¹⁸ The subject of global flows of medical technology and transnational market strategies is much too large to fit within the scope of this study and would require a completely separate research with a different setting and significantly modified research methods. I will in this thesis make a couple of brief references to some other studies that have addressed the subject, and that may help clarify the broad macro-context wherein the cutting-edge medical technology, such as mechanical help-hearts, is situated.

and clinical practices, as well as what the effects of these conditions might look like. On a broader level, the aim is to articulate the circumstances through which the communities of “success-story” medical cases come into being, to show how cultural norms, values, and moral codes are related to such circumstances. Ultimately, I intend to show how such norms spread through understandings expressed through formalized clinical practices, i.e. high-tech medical healing rituals.

QUESTIONS

Considering the aims, I ask the following questions:

- How are local ways of being, feeling, and knowing manifested in the ways in which mechanical help-heart treatment is performed?
- How do the ways in which mechanical help-heart treatment is performed influence the participants’ understandings and experiences of the body, life-threatening chronic illness, death, healing, and medical technology?
- How is the outcome of the mechanical help-heart treatment conceptualized, experienced, and negotiated among the actors involved?

More exactly, with the first question I seek to understand how the structure of ritual performance assembles people into the joint enactment of cultural ideas upon which these formal procedures are built, and also how these cultural understandings are ritually expressed. With second question I seek to explore how this specific ritual expression of cultural ideas provides medical professionals and ill persons with interpretational logic for attribution of meaning to the misfortune of illness and to their agreed-upon ways of dealing with it. I also examine what kind of values and sensibilities linked to threatening death, body pains, and belief in power of medical

technology and knowledge are generated and embodied through these practices. Inherent to this question is also how ill persons make sense of their situations and of themselves; provided that our identities are continuously being negotiated in a dialectical relationship between ourselves and our ways of engaging in our social and cultural environments, how does this treatment influence ill persons as individuals and as members of a society? In other words, how does the treatment influence their identity and their future hopes and plans and how does it affect their relations to their sociocultural environment? Furthermore, what sensibilities can be discerned during the course of treatment and during the ill persons' interactions with society outside of the hospital and how are they managed? I also seek to understand what role biomedical technology involved in the treatment of heart failure is ascribed by the professionals working with it as well as by the people whose lives depend on it. In what ways is this kind of technology integrated into their daily routines? Finally, with the third question I seek to discern what kind of challenges emerge with the performance of mechanical help-heart treatment. How are these challenges understood; how are they met; how is the meaning of these challenges expressed through these practices? Does the treatment lead to the desired goals for everyone involved? Are understandings regarding the goals of the treatment shared or contested? At what point of the treatment, and on what grounds, are they shared or contested?

It should be made clear here that the tripartite structure of Part II, the empirical part of the thesis, is organized into three empirical chapters so as to correspond to the tripartite chronology of rites of passage (separation, transition, and reintegration) and not to the three research questions displayed here¹⁹. In this way I hope to provide the most comprehensive account of the ritual character of the mechanical help-heart treatment. However, all three research questions are still

¹⁹ Although a third and last research question happens to correspond pretty well with the third and last empirical chapter CHAPTER SIX – REINTEGRATION (pp 323). This, however, is a coincidence.

relevant and present throughout the entire empirical part of this thesis.

The point of this research is to critically examine, from a cultural perspective, the sophisticated and highly intricate nature of these practices in order to ultimately distinguish what kind of challenges emerge with their implementation. My main argument is that, while advances in medical technology and practice bring relief and joy to many, they also bring uncertainty and various challenges that appear to be difficult to anticipate beforehand. Hence, with this research I make a twofold contribution:

1. First, on a practical level, I believe that a qualitative distinction and explication of these challenges may: a) help to make future challenges less unexpected, and b) provide clues of how to improve the practical ways to meet them.
2. Second, on a theoretical level, I hope that an analysis and discussion of the social and cultural dimensions of these practices may help in understanding and appreciating: a) the significance they have for how we perceive ourselves and the world we inhabit, b) the vast structural political and economical forces at work; c) the patterns and scope of technological and medical developments and the impact they might have on the future prospects of mankind, and d) the implications that the particularity of making the institutionalized scientific and technological practices the object of critical scrutiny from a cultural perspective have on the future study of rituals in general.

In order to make sense of the details I ask some more general questions: what can we learn about the medical staff and the patients by looking at these practices; what can we learn about ourselves by learning about these people? Ultimately, how are these practices, in the face of neoliberal expansion, interconnected with global flows of medical technology and their incorporation into state building

processes, new market strategies, and governance and citizenship in Sweden?

STRUCTURE OF THE THESIS

This thesis is divided into three main parts. PART I consists of one introductory chapter and three more specific background chapters. In CHAPTER ONE - BACKGROUND, I aimed to provide some background information about the subject and the scope of this study. I started by portraying the multiple character of the heart and various meanings attributed to this remarkable organ across times and places. It was my hope here that a somewhat deeper and broader contextualization can be achieved by a brief historical outline of the ways human heart has been conceived and portrayed through time and space, and the way it has been related to technology. I continued with a brief account of heart related diseases on a global scale to particularities of heart failure, the technology developed and deployed to deal with it, to the subject of the human heart and its vicissitudes, and on to outlining the research aims and questions. I also tried to outline some detailed facts about mechanical help-heart technology and also to give a short illustration of the rise of medical technology and the development of the mechanical help heart. CHAPTER TWO – METHOD is about research methods and describes the site, actors, and process of ethnographic fieldwork. CHAPTER THREE – THEORETICAL FRAMEWORK addresses theoretical perspectives and some central concepts used in this study.

PART II is the empirical part of the book and consists of three chapters. CHAPTER FOUR – SEPARATION describes the clinical practices through which the patient is diagnosed with end-stage heart failure and selected for implantation of a mechanical help-heart. CHAPTER FIVE – TRANSITION revolves around pre-operative, operative, and post-operative phases of this treatment. CHAPTER SIX - REINTEGRATION is about discharge and life at home.

PART III is composed of one concluding chapter, CHAPTER SEVEN – DISCUSSION, that provides theoretical discussion against the

backdrop of empirical chapters before. Here, I provide a summary of the results of this study and expand the discussion to the related topics of more general character – the global nexus of technology research and development and the Medical Industrial Complex (MIC), the idea of progress, neoliberal expansion, new market strategies, etc. Finally, I draw some conclusions and connect them to the idea of progress and the ways in which this concept is embodied through the practices of implanting mechanical help-hearts.

CHAPTER TWO – METHOD

I THE SETTING

This thesis is based on nine months of participant observation in a heart disease department at a large academic hospital in Sweden. More exactly, I have spent a total of one hundred and thirteen days in this hospital, talking to people, attending their various meetings, following their daily routines, and also corresponding with some of them by mail and telephone. This resulted in one thousand and eighty-five pages of typed field notes, more than sixty-one hours of audio recordings of a variety of meetings, ward rounds, conversations, and surgical treatments, and roughly two and a half hours of video-recorded open-heart surgery.

In this chapter, I start by presenting the setting and the people studied. This is followed by a brief account of painstaking negotiations for access to the field. Then I go on to discuss the details of conducted field work, data collection, and data analysis. After this I discuss the methodological implications of the translocal character of the field, followed by a discussion on the significance of an ethnographer's emotional experience of the field. Finally I round off with ethical considerations. Before we get into details of data collection methods, challenges and strategies, a few facts about the setting and its people would be in order.

HEARTLANDS

Various people who are engaged in daily work at the hospital where I conducted my field work are most often recognized and referred to as expert doctors, nurses, and assistant nurses – something they take much pride in and seldom hesitate to emphasize. This hospital is one of ten modern university hospitals in Sweden. It has several hundred beds and nearly five thousand employees. Besides being a place of

advanced health care it is also a place of research and training. Hundreds of thousands of people from all over the region come here to seek help, and people from all over the world come to seek biomedical and/or health-care training, as well as career opportunities. For many, it is a place of rescue. For others, it is also a place where biomedical knowledge is continuously being built. Among other things, the professionals here specialize in various diseases of the interior surface of the eye, neuromuscular diseases, spinal deformations, sex-change surgery, accident surgery, highly contagious diseases, and particularly, heart-related diseases. What's more, these experts offer diagnostics, consultation, and treatment in all medical areas of expertise, with only one exception – organ transplantation.

The part of the hospital dealing with cardiovascular diseases is composed of three large clinical departments: 1) the Department of Cardiology; 2) the Department of Radiology; and 3) the Department of Cardiothoracic and Vascular Surgery. Here, cardiology, diagnostic and interventional radiology, nuclear medicine, intensive care unit, thorax and vascular surgery, five wards of different specialties, and a reception area are all assembled into a highly modern part of the hospital. This organizational (spatial) gathering of various biomedical areas of expertise and occupations creates closeness and immediacy, thus generating conditions for smooth multi-professional cooperation with the aim of giving cardiovascular patients an effective chain of diagnostics, treatments, and care. This part of the hospital is where I spent nine months doing participant observations, and it will henceforth in this book be referred to as the 'Heartlands'. This is not a direct translation – because the original emic term in Swedish is unique for this hospital, a direct and idiomatic translation would jeopardize the rule of professional secrecy. The suffix '-lands' is chosen with the aim of portraying the spatiality of the setting. Furthermore, while revealing the real names of places and persons would breach the rule of professional secrecy, providing the conventional "X" or "Z" pseudonyms might risk making the facts of

real setting decontextualised and dehumanized. This way of naming the research setting is an attempt to put this particular site of ethnographic inquiry on par with any other, perhaps more anthropologically traditional, site. In other words, by using the name 'Heartlands' I hope to: a) portray this place as culturally unique yet anthropologically familiar, and b) because medical professionals enjoy a high social status, I use this translation to “even the balance of power” when studying the powerful (Gusterson 1997; Hertz and Imber 1995; Latour and Woolgar 1979[1986]).

The different departments and centers of key medical practices of Heartlands are strategically localized in a three-floor building, annexed to the main hospital building, according to the facilities provided by the management. The Department of Cardiology (first and second floors) consists of Outpatient Reception, Heart Failure Ward (further divided according to medical specialties into the heart failure side and the arrhythmia side), Heart Intensive Care Unit, Vascular Ward and Ischemic Ward. The Department of Cardiothoracic and Vascular Surgery (third floor, i.e. top floor²⁰) consists of the Cardiothoracic Ward, the Thoracic Intensive Care Unit, the Thoracic Surgery, the Vascular Surgery, the Thoracic Recovery Ward (post-surgery step-down unit). Finally, The Department of Radiology (third floor, after passing the Department of Cardiothoracic and Vascular Surgery) is divided into the Division for Clinical Radiology and the Division for Nuclear Medicine.

In many ways, Heartlands is a protected and secluded place composed of a variety of areas with different levels of access restriction²¹. The hospital in which it is situated is, viewed from the outside, the tallest and beyond question most dominant building around. During my nine months here, I have never encountered anyone who had no business being in the Heartlands. The Thoracic Intensive Care Unit and Thoracic Surgery are a part of Heartlands

²⁰ More about the cultural significance of architecture in the 'Architecture of hope' section (pp 249)

²¹ See 'Architecture of hope section' (pp 249)

with the highest level of access restriction; special pass cards are issued to the employees working here for access. Visitors, such as me, can be granted a temporary pass card but are expected not to move around freely without notifying the duty doctor in advance. Heartlands is also that ‘other space’, separated from the rest of society, a place that is “... absolutely different from all the sites that [it reflects and speaks about]”, much like places Foucault referred to as *heterotopias* (Foucault and Miskowiec 1986: 24). In fact, viewed in the light of some of the principles of heterotopias emphasized by Foucault, Heartlands can be regarded as not very unlike the mystical secret houses in tribal societies:

Heterotopias always presuppose a system of opening and closing that both isolates them and makes them penetrable. In general, the heterotopic site is not freely accessible like a public place. Either the entry is compulsory, as in the case of entering the barracks of the prison, or else the individual has to submit to rites of purifications. To get in one, one must have a certain permission and make certain gestures. (Ibid: 26)

It was my job to learn these gestures, not only in order to gain the permission of entrance, but also to gain the appreciation of acceptance from the peoples of Heartlands – the Heartisans.

HEARTISANS

The Heartisan community is divided in three main hierarchical segments: 1) doctors, 2) nurses and assistant nurses, and 3) hospitalized patients. Whereas the doctors are regarded as endowed with the power to cure, nurses and assistant nurses are usually depicted as the ones with the power to care, and finally the patients are the ones whose power is limited to compliance. Other peoples of the Heartlands are administrative and maintenance personnel.

Doctors make up the most powerful group within the Heartisan community. These professionals are eager problem-fixers, inquisitive scientists, knowledgeable consultants, pragmatic achievers and service

providers. Together with the nurses and assistant nurses they make up the bulk of the Heartlands – I call them ‘Heartisans’²². This term is²³ mainly chosen in order to put an emphasis on the medicine as practice (*artisanship*), something that needs to be done by a skilled craftsman in order to come into being. Or, as professor Nordenfelt expressed it during one of the weekly seminars at our department, “Although medicine rests on the shoulders of science – it is just a practice!” (Nordenfelt 2010, my translation). What’s more, in addition to having the know-how and being endowed with practical skills in the art and artisanship of biomedicine, Heartisans are often discursively depicted as fighters (so we can think of them as military *partisans*) in biomedical warfare on sick hearts (Coulehan 2003).

Amongst the doctors, various Heartisan tribes²⁴ are divided up according to their different medical specialties. Each of the three departments belongs to a certain branch of medicine – cardiology, radiology, or thorax surgery. The thorax surgery is a complex mixture of two additional medical disciplines – surgery and anesthesiology. Besides being divided, in accordance with the different areas of their expertise, into cardiologists, radiologists, surgeons and anesthesiologists, Heartisans are further differentiated according to sub-disciplinary expert knowledge into ischemia cardiologists, heart failure cardiologists, and arrhythmia cardiologists. Radiologists are divided according to their specialization in various visualization and diagnostic technologies. Surgeons operate within the areas of general vascular surgery, renal vascular surgery, cardiovascular surgery, heart bypass surgery, heart valve surgery, and mechanical help-heart surgery. Cardiovascular surgeons are a group of their own, focusing only on the heart. A surgeon usually masters more than one surgical specialty and can utilize his/her knowledge in several different – or all

²² Patients are also being integrated into Heartlands as a particular segment of Heartisan society (pp 111, 168, 218, 243).

²³ In addition to the reasons provided above regarding the use of term ‘Heartlands’.

²⁴ The term ‘tribes’ is also used here for all the same reasons that I gave regarding the use of the terms ‘Heartlands’ and ‘Heartisans’ (pp 61-65).

– domains of thorax surgery²⁵. Of all the thoracic surgical fields at the Heartlands, the implantation of mechanical help-hearts is considered to be supreme and is thought of as the final goal of surgical learning for all surgeon-Heartisans.

Besides the doctors, each tribe consists also of Heartisan nurses, assistant nurses, administrative personnel, and patients. Each of the tribes is subject to strict hierarchy with a clear chain of command, including Heartlands management, chief of the department, chief of the staff, chief (senior) doctors, specialist doctors, aspiring novices, head nurses (with some kind of specialization), nurses, and assistant nurses. In the practical everydayness of the Heartlands, however, it is mainly the chief doctors who call the shots. Inherent to this chain of command is the underpinning chain of compliance. Doctors consider themselves to be compliant with the laws of nature, objective facts and evidence-based knowledge; nurses and assistant nurses comply with orders given by doctors; and patients comply with orders given by doctors, nurses and assistant nurses. Finally, the complexity of Heartlands structure, with its various professions bundled together under one roof, is marked by power relationships and interests. This is manifested in intricate repertoires of legitimizing discursive strategies among individuals and different groups. Their professional roles, their places and statuses in the Heartlands are daily negotiated and justified with reference to expert knowledge, professional competence, organizational efficiency, and patient-centered perspectives. Sander's and Harrison's study of professionals working with heart failure patients in the English National Health Service (ENHS) shows a similar network of continuously contested and negotiated relations (Sanders and Harrison 2008).

The patients, the temporary visitors to the Heartlands, come in great numbers and have a relatively quick rate of turnover. There are various different points of entrance into the Heartlands and also various different routes to the exit. Some patients are coming for their

²⁵ With the exception of heart transplantation, as it is not practiced in the Heartlands.

annual check-ups in an outpatient consulting room; some are here on their own initiative requesting medical examination and consultation; some are remitted from primary clinics or other hospitals; some get here from other parts of the hospital; some arrive through the Emergency Room. Others arrive by emergency helicopter; some, on the other hand, are here for a post-operation follow-up examination. Some are sent home with advice, some with drug prescription, and some with some kind of polyclinic treatment done. Some never make it home. Some are admitted and provided a bed in one of the wards for observation and treatment. Some become subjects of an extensive series of complex treatments requiring all three departments' attention for an indefinite time. The treatment of some patients even extends the scope of the hospital to close collaboration with other hospitals. For some of the patients this is a starting point in a series of biomedical treatments. For some, it is just a part of the route to other parts of the hospital (or other hospitals), while for others it is a final destination. Although being but a 'guests', the patients also become Heartisans during the temporary transit through the treatment. This means that they are provided a certain status position and role among Heartisans, and also that they are taught to abide by the Heartlands rules and norms, all of which are considered indispensable for the success of the treatment.

II ENTERING THE FIELD

AT THE GATES

There is nothing easy about trying, as an outsider, to enter the world of biomedicine. To begin with, hospitals – being heterotopias (Foucault and Miskowiec 1986) – are not particularly inviting places and are often distinguished by the "... defensiveness of hospital authorities and their hesitation in allowing observers to enter their workplace" (van der Geest and Finkler 2004: 1996). The fact that my research questions and aims are foreign to the world of medical

research did not help. Thus, several initial meetings with some of the main gatekeepers of the Heartlands, where I tried to present my ideas, resulted mostly in wavering and hesitation on their part and, in the end, in scheduling yet another meeting. The gatekeepers consisted of a handful of key actors with high positions in Heartlands' hierarchy. With approval from the regional ethical committee in my hands I was ready for negotiations – what I didn't know was that these negotiations would go on for nine months²⁶. As the gatekeepers proved to be extremely busy²⁷, during these nine months I had the chance to meet with them on only a handful of occasions.

During the very first meeting my research questions were referred to as 'adjacent' in relation to the medical-technical ones. At our next meeting I was advised by a senior surgeon to be careful not to forget that the patients I aim to study are in a very vulnerable situation, while at the same time underlining that "we too", i.e. medical staff, are "all in a very vulnerable situation". I understood that my presence as an anthropologist, if perceived as disquieting, might have a negative impact on the work of the medical staff and thus directly on the patients' health. Still, I also sensed that this was a remark making it clear to me where the lines are drawn; they separated an *them* (doctors, nurses and patients – the Heartisans) from *us* (social scientists – the outsiders).

My request for at least a couple of months of time for my field work was met with terms like "impossible" and "incredibly demanding". My methods were systematically questioned and it was made clear to me that recognition of different kinds of knowledge, apart from the medical one, shouldn't be expected – let alone taken for granted. Not all of the gatekeepers were reluctant, however. I still recall Fredrik, a young thoracic surgeon, as he was skimming through

²⁶ Just as long as the subsequent fieldwork.

²⁷ All of whom are clinicians, practicing medicine, and the majority of whom are also academics involved in various scientific research projects.

the copy of the *Written information – pt I* document²⁸ and finally breaking the silence with a surprising, “This is fucking great!”. At the end, at last, I was granted one month of field work as a trial.

It should be made clear here, however, that this was no more than one battle won. At this point in time I didn’t realize that my struggle for access was in fact an open-ended project that was never to be completed. At times, during these initial meetings, some of the doctors were undeniably friendly, yet cautious and protective; at other times they were overtly suspicious, unresponsive, and critical. After gaining access I learned that each and every day in the Heartlands I would have to keep my eyes wide open for whatever was going on and to struggle continuously to enforce the gained permission to see, permission to hear, and permission to take notes about what was going on. I soon realized that different members of the medical staff had different opinions about my presence there. Subsequently, some of them have developed different strategies to erase or close their eyes to the access I was granted. They also developed different ways of legitimizing those strategies. The entrance granted into Heartlands was by no means to be confused with access granted to everything taking place there. The character of my access changed from day to day, from person to person, and from situation to situation.

III ETHNOGRAPHY

‘AT HOME’?

Imagine yourself suddenly set down surrounded by all your gear, alone on a tropical beach close to a native village, while the launch or dinghy which has brought you sails away out of sight.

(Malinowski 2002[1922]: 4)

Imagine yourself suddenly standing in the middle of a hospital corridor, surrounded by ominous dim yellow light and the bizarre

²⁸ This one page document is written for the patients but was used to inform medical staff as well.

sharp odor of alcohol-based hand rub, alone in the middle of a swarm of strange people rushing around dressed in white, at the heart failure medical ward close to... well, both to your home and your workplace, actually. In fact, I was surprised that conducting anthropology at home could be as dramatic and exciting as Malinowski's account of his arrival onto the sandy beaches of the south coast of New Guinea. Real *and* strange indeed²⁹! This feeling confirmed for me that the hospitals, in fact, are heterotopias – isolated, odd, and somehow unreal. Heartlands emerged as a backstage world of what most of us usually associate with medicine and health care in our society, i.e. primary care and pharmacy. It is a place where people get hospitalized and where complex and time-consuming treatments and research on the human heart is conducted. The backstage passes, however, are reserved exclusively for the invited.

I still recall, ever so vividly, how just standing there in that corridor, on that Monday morning, felt surreal and oddly dreamy. First and foremost, it was an immense relief after nine months of exhausting negotiations with Heartlands management to get my hands on that backstage pass. Second, Heartlands is a rather exotic and exciting place; it is a place where life and death seem much more present and apparent than in primary care and in the society at large. It is also a place where the people working there seem unusually devoted to their calling – mending sick hearts and saving lives – and where the latest medical knowledge and technology are the very backbone of the everyday practice.

There are certain advantages to conducting anthropology at home. For instance, language barriers are most often not considered a problem. However, I often found the professional and organizational language of the medical staff extremely hard to comprehend – at

²⁹ This exotic quality is, of course, not a property of hospitals alone in our society; the same could be said about almost any place majority of people rarely have the opportunity to enter. These might be police stations, construction sites, waste disposal sites, law firm chambers, military weapon factories, and insurance companies.

times even impossible. In order to understand what was said, I had to learn that language. Hence, I got hold of an armful of medical textbooks, books on medical abbreviations and acronyms, as well as some cardiology course books – and I started my language training. Probably the best thing with anthropology at home is the relative proximity to the safety of your own home, where friends and family can share your excitement when you are in high spirits, or comfort you when times get tough. Still, as will soon be evident, this supposed ‘closeness’ was also in my case altered by the emotionally centripetal power of the field³⁰. In general, as is the case with any kind of anthropological conduct, there are challenges to be surmounted by the researcher: I needed to get close to the people I studied – although not too close. This is the omnipresent dilemma of ethnographic work. At first I was wondering how I, as a professional ethnographer, should relate to the taboo of ‘going native’ when ‘them’ is ‘us’? How was I to deal with the blindness caused by my hyper-closeness to the setting? Most of these worries proved to be rather superfluous. Indeed, the fact that I was aiming to explore a relatively unfamiliar domain of life rendered the whole ‘fieldwork at home’ concept an oxymoron. Can an anthropologist ever really be at home in the field? Others have also been critical of the connotations ascribed to the concept of home discussed here and also of the alleged home-blindness of anthropology in familiar settings (Hadolt 1998; Hastrup 1995; Peirano 1998). Ultimately, to me Heartlands was *terra incognita* – I was an alien.

Being a part of a hospital, Heartlands also makes part of “... the premier institution of biomedicine cross-culturally ... *a domain where the core values and beliefs of a culture come into view*”, (van der Geest and Finkler 2004: 1995, 1996, emphasis in original). Here, the universal issues of life, death, health, are understood and practiced in a particular local ways. At the same time, the local culture is shaped by the power of global biomedicine. The hospital is a prism, a place of

³⁰ See the ‘And the anthropologist made the ‘Emotional Note’ section (pp 101)

interface between micro and macro – between the particularity of the local culture and the strong dominance of the global biomedicine.

Apart from what is said in the media, movies, series, and reality shows³¹ – what do we, the lay people, know about daily life in a modern Western hospital? While we all have experienced this world in one way or another³², we are usually confined to the role of a body to be treated and cared for. We are never granted access to the whole scene of the hospital. What we learn is mostly what concerns our individual (or a family member's) illness and the offered treatment plan. Occasionally, we might even engage in a moving encounter with a nurse or a doctor. We can share a laugh or a few tears with them or we can end up in disagreement and experience disappointment, anger, and frustration. Still, most people rarely write any comprehensive accounts about these experiences, and even if they did they would probably fail to account for much of what is yet to be learned about this puzzling place.

It is hard to reside “... right among the natives”, (Malinowski 2002[1922]), as none of them actually lives in the hospital; it is no one's home. Medical staff comes here to work and patients to get checked-up, to get better, to get well or, perhaps, to ease the pain – or even to die. The hospital is per definition a place of passage – a liminal place³³. Thus, it cannot be considered as completely isolated from the rest of the society. In that sense, the ethnographer is in fact residing right among the natives, i.e. the community writ large, as he or she is living in the same or at least a nearby-municipality as where the informants live. But the municipality, however important for

³¹ Not that this type of discourse should be neglected as insignificant – it is just not sufficient as the sole source of our information on hospital life and practices.

³² Most people in developed world have had occasional encounters with biomedicine - some people even spend most of their lives in and out of hospitals.

³³ See the 'Rites of Passage' section in CHAPTER THREE – THEORETICAL FRAMEWORK (pp 143) for more details on notion of 'liminality'.

contextualization of the ethnographic evidence, is not the main site of the study. The hospital is!

Hospitals are interesting sites for social scientific research in that they are: i) complex social organizations, ii) they have complex relation with technology, iii) they have their own language that is often impenetrable from the outside, iv) they have their own clothes, v) patients are denuded of their own identities as they are absorbed into system and are redefined as “patients” or “the old man in thirty-six” or “the arrhythmia in room 19”³⁴.

The ethnographer’s role

How is the ethnographic method of participant observation to be carried out in a modern hospital? First and foremost, it is necessary for the ethnographer to take on a certain role in the field. If the ethnographer aims to blend in and become a natural part of the hospital environment there are generally three common ways of doing it, (van der Geest and Finkler 2004: 1998). First, the ethnographer can join the staff. Most of the ethnographers end up here and accept the role of non-treating parts of the staff. They may put on a white coat, (Latour and Woolgar 1979[1986]: 255; Mol 2007[2002]: 2)³⁵, or some other kind of uniform proper for the environment in question, thus being perceived by the patients (or doctors and nurses) as one of the staff. Second, the ethnographer might join the patients. In general, this is practically more challenging and ethically more controversial. There are few examples of ethnographers engaging in undercover field work as patients with only a few members of the staff knowing about it (van der Geest and Finkler 2004). However, self-ethnographic observations where the ethnographer takes notes and analyzes his or her own experience of the illness and the health care

³⁴ More about this in CHAPTER FIVE – TRANSITION (pp 221).

³⁵ Latour and Woolgar’s work took place in a scientific laboratory – yet resemblances are many. For instance, both are places of scientific research and are thus also the places where the knowledge is produced; both are places of status and power which turns the knowledge produced into a continuous flow of widespread evidence-based facts.

are more common. Third, the ethnographer can join the visitors (the friends and relatives). This way of conducting hospital ethnography is particularly useful when the ethnographer is focusing on the patients' relatives. The status position of the visitor provides the ethnographer with the possibility of participating naturally which retains more clearly the role of ethnographer by extending the concept of whocounts as visitor (van der Geest and Finkler 2004).

On my first day in Heartlands I was, without delay, put through the rapid ritual of initiation into Heartisanhood. I was tagged and couldn't escape experiencing the metamorphosis of my appearance. To be precise, I was provided with a name-tag embellished with a Heartlands logo (a stylized heart), my name, occupation (PhD student), and the clinical department that was essentially my home base during the fieldwork (The Department of Cardiology). Name tags such as this come in red plastic holders that are attached to the breast pocket of a white shirt or white coat, and thus are visible to anyone who wishes to know what position the tag-owner holds – Medical Student, Registered Nurse, Assistant Nurse, Chief Doctor etc. Tagging is a strategic measure that makes the work in a multi-disciplinary environment such as Heartlands less problematic, especially in time-limited situations when there none over for conventional ways of making acquaintances. I was also given a magnetic card which allowed me to enter and move around most of the Heartlands' different areas with no hindrance³⁶. Furthermore, I was provided with my own locker in one of the locker-rooms and was guided to the clothes-storeroom where I was urged to choose an outfit. There were various styles of white garments³⁷. Other departments, for example the Department of Cardiothoracic and Vascular Surgery, had blue and green garments. As I moved across

³⁶ With the exception of the Surgery area which was highly restricted; access to it can be granted only by the operating surgeons and anesthesiologists.

³⁷ With only one exception – pale blue – which wasn't as popular among the staff (I have encountered less than a handful of the Heartlands employees wearing it) I figured it would make me stand out – probably not so much of a blending *in* as I was looking for.

the Heartlands, changes of my outfit were required. When attending the surgical procedures I was asked to change into the blue outfit³⁸. Minutes later, I was dressed in white: white shirt, white pants, and a white coat. I must admit that there is something about this white coat! I positioned myself in the front of the mirror placed above one of the sinks in a dressing room, took out my cell phone, took a snapshot of myself, and sent it to my mother. This is the first thing I did! Several months after the field work, I mentioned this to an acquaintance who is a medical student herself. “Oh, well, that [taking a ‘white-coat’ self-portrait with the cell phone] is the first thing everyone does”, she responded. I wasn’t shocked. Putting on the white coat seems to be a symbolic rite of taking on a new identity. It seems to carry the significance of a silent initiation rite observed in solitude – with yourself, for yourself. I can still recall, so vividly, how I couldn’t help but feeling, besides finding the situation I was in a bit surreal, a little bit of pride. So I had to share this feeling – hence the text message sent to my mother. Well aware of the temporary character of my metamorphosis and that it was all make-believe (in contrast to that of the real young soon-to-be-doctors who have devoted their entire lives to this calling), I still liked the idea of entering the uniformed group that make up medical society, of wearing the “physician’s white coat: a potent ritual symbol of the healing powers of medical science”, (Helman 2001[1984]: 12-13, 157-158). I belonged! I had my name-tag, the magnetic card, white pants, white shirt, and white coat. Yet, at the same time, I was embodying the notion of an anthropologist – I blended in... I was camouflaged... I was on my way to become a real anthropologist! So, I took out my notebook, checked the batteries in my sound-recording device, armed myself with pens and went upstairs to the heart failure ward. Later on, I utilized my freedom to choose when and where to wear the white coat – or not. The coat became quite a good tool; when associating with the doctors, attending their meetings, I always wore the coat; when associating

³⁸ More about the significance of garment colour in CHAPTER FIVE – TRANSITION (pp 221).

with the nurses and patients, I tried to remember to take it off. By this strategic shedding of the symbol of authority I found the interaction with the nurses and patients a bit less strained. While wearing the coat, on the other hand, I managed not to stand out as an outsider among the doctors. Of course, this was never as easy as it might seem. Even if medical staff and the patients might have gotten used to my presence and at times even acted as if I really belonged, I was still unmistakably an outsider.

The oxymoronic axiom of anthropological practice – participant observation – is traditionally the first real thing that “defines the space of anthropology” (Rabinow 2007[1977]: 79) and the anthropologist, both for the anthropologist and for the people studied. The paradox of this term, and the practice it denotes, is supposed to be in the intrinsic and continuous tension lying between these two polarities – of participating and observing. ‘Participating’ means immersing oneself in the flow of daily practicalities. ‘Observing’ means taking a step back and letting it all sink in. The former is an insider’s practice; the latter an outsider’s. Yet this simplification doesn’t quite do justice to the actual way things work in the field. In practice, these two terms are not so easily separated. My experience was that I observed through participating and participated through observing – there was really no clear-cut discrimination among the terms. The only fact that might have put my participating in an inferior position in relation to my observing is that I never could fully engage in the clinical practices the way medical staff did. In spite of my white coat there was no real clinical role for me to take on. Apart from occasionally acting as an interpreter for patients from former Yugoslavia³⁹, my participation consisted of no more than sporadically assisting a nurse, an assistant nurse, or a physiotherapist by fetching some material or equipment, giving a hand in lifting and handling less mobile patients, or carrying and serving trays to some patients. I also could confirm or contest the reported information about the patient or about the treatment during

³⁹ Which was both time saving and economically beneficial for the Heartlands as the doctors and nurses didn’t have to wait or pay for a professional translator.

the routinized hand-over talks (or remind about something that slipped the reporting nurse's or doctor's memory), attend regular meetings, ward rounds, and walkabouts, and join the others on their coffee breaks and lunches.

The researcher's position

As early as during the initial negotiations, I experienced the same kind of justification crisis regarding my interest in the Heartlands as Rabinow describes in his engaging book *Reflections on Fieldwork in Morocco* (Rabinow 2007[1977]: 77). Why would a rich Westerner move to a poor village to live alone in a mud house, the Moroccan locals wondered. This description fits perfectly what I experienced while trying to get the people of the Heartlands to accept my presence. Why was I there? Why Heartlands? It was considered rather odd for anyone who wasn't in the line of health care work to voluntarily want to get into the hospital and spend so much time there. What was I to answer? It's my style: I just love to dwell in murky places of human suffering⁴⁰?

An ethnographers position in the field is always artificial, frail, instable, contingent, and odd (Crapanzano 2010: 77). At first, while I was a new face at the scene, people would either glance at me curiously, trying at the same time to catch a glimpse of my name-tag without being too intrusive – curious enough to stare at my chest yet not curious enough to pop a question – or address me about some subject matter just as if I was a doctor⁴¹. Some would reach out for a hand-shake and greet me with: “Oh, so you are the one that is going to study what we do here and all that! Welcome, my name is ...”, and so on. Others would just pretend that I wasn't there. I held short presentations for the staff members on appointed occasions. However, because there are over five hundred people working in Heartlands, in four shifts, I soon accepted that these presentations of who I am and what I am doing here are not an act of courtesy

⁴⁰ In fact, I did study convicted felons for my Master's thesis.

⁴¹ This was the most frequent mistake people made about me.

belonging to a given point in time but rather one amongst several other never-ending projects that were part of my field work⁴².

The attempts to describe myself to medical staff made me think about myself and my role here. First of all, I am not a native Swede but rather what can be called a Bosnian-Swede, as I was born and raised in former Yugoslavia. This fact positioned me in an in-between space. In that sense the issue of “being a ‘native’ among the natives” (Van Dongen 1998: 279) was not so much of an issue for me. My hereditary ascribed cultural self and my acquired one composed a dual frame of reference providing me with an ever-present backdrop of contrast. In other words, when focusing on the Swedish aspect, I couldn’t help but seeing it with the Bosnian aspect in the background – and the other way around. My gaze moved like a pendulum – always comparing. I suppose there are both advantages and drawbacks inherent in this circumstance. First, I lack large chunks of tacit cultural knowledge, shared history, and collective memory of the Swedish people. I am not totally clueless, but it is safe to say that I got a really late start in comparison to the natives. Hence, I lack the knowledge that would provide my ethnographic evidence with much deeper contextualization. On the other hand, I take fewer things for granted. Having ‘always comparing’ as my default mode made me notice certain things to which natives might have been too accustomed. This does not mean that I have had a more accurate ethnographer’s eye, but rather that my constant ‘in-comparison’ mode of observing kept me alert. All of this is, of course, a reflection on my perspective – on the scope of my gaze. Nevertheless, my immigrant identity might also have colored the way people of the Heartlands perceived me. I do have a solid command of the Swedish language on an advanced level. But my non-Scandinavian looks and my accent readily reveal my immigrant background. This means that I, at times, had to try even harder in order to gain recognition and acceptance.

⁴² Taking notes, getting used to blood, suffering, death, continuously working for acceptance and access, following the rhythm of the field, etc.

Regardless of the fact that my field work took place at home it would still be misleading to think of me simply as a native among the natives. I was an outsider! It was not because of my immigrant background and accent, nor was it only because of the fact that I didn't belong to some medical profession. It was mostly because I acted and spoke differently and, as I said earlier, I had no real job to do – no real clinical role. In addition to having trouble understanding what was being said and also making myself comprehensible – due to the fact that I just didn't speak Heartisan language⁴³ – and also in addition to my childish and sometimes downright weird questions and actions, I also managed, on several occasions, to commit breaches of etiquette.

At the same time, I was often regarded as a goofy stranger “whose mistakes could easily be forgiven” (Van Dongen 1998: 281). People would turn to me to tell me a story that they thought I might be interested in. They used various strategies to publicly display their awareness of me to the rest of the staff. They spoke often about me taking notes on them: “Oh, there you sit with your note-book and pen and write down all the intrigues taking place here... some book that's gonna be”. Such remarks, joyful and in a spirit of friendship, would usually provoke an equally cheerful assent, “Yes, while pretending to do some kind of research he is in fact just sneaking around and sniffing out scandal-stories to write about”. They all knew, of course, that I was doing serious research (even if that fact doesn't rule out scandal-stories). But this ritual mockery is something that nurses and assistant nurses also do with each other in order to bond and to reinforce their relationships. Victor Turner's concept of ‘status reversal’ is quite a useful theoretical tool with which this practice can be elucidated properly (Turner 1997[1969]: 176). The absurdity of this pretend mockery seems to function as a way of nourishing the team-spirit and mutual respect; the liminal phase of mockery is performed as make-believe and belongs to the imaginary world of humor which makes its opposites – the team spirit and

⁴³ Local professional jargon and terminology typical of Heartlands.

mutual respect – indisputably real. By inviting me into this ritual, nurses were displaying acceptance.

Doing the field

Apart from a few weekends and nights spent at the hospital – in order to experience the hospital at night and the hospital during the weekend – and also apart from my keeping the diary, my working days would usually start at eight o'clock in the morning (when the first bus arrives at the hospital) and end at five o'clock in the afternoon. This schedule was observed Monday to Friday and is a replica of conventional working hours in Sweden. Hospital working hours differed somewhat; nurses started their work at seven a.m. and ended at three p.m.; the new shift arrived at two p.m. and went home at ten o'clock in the evening; the graveyard shift went on from ten p.m. to seven o'clock the next morning. Because of several practical reasons it was difficult for me to fit my fieldwork schedule to exact working hours of medical staff. Still, I regarded the eight-to-five solution to be close enough. What's more, there were also times when I observed a full nurse-day. Furthermore, there were also times when I worked in the field for three shifts non-stop, as for example the Christmas Eve when I socialized with the medical staff and participated in their special Christmas *knytkalas* ritual – the annual Christmas pot lock meal where Heartisans would bring good food from home and share with other Heartisans in a ceremonial atmosphere. That night I also met the family of a dying man – three grown-up daughters and a wife, and stayed with them throughout the night, just being there, listening, sharing the load, having time for them, watching their beloved father and husband take his last breaths... for many long, agonizing hours.

Leaving the scene of the hospital to go home each day was exactly what everyone working at the hospital also did. I was not unique in that sense – on the contrary, that allowed me to *participate* in yet another practice of what medical staff does – swinging to and fro

between two worlds, the biomedical one and the private one. No one lived at the hospital – it was no one’s home.

One of the things that became apparent the very first week was that there are no short-cuts in ethnographic work and that much of my fieldwork would require patience. What I was looking for wasn’t to be found in isolated occurrences, regardless of how spectacular they might be. I was aware of the fact that the significance of gathered evidence can only grow with its thickness (Geertz 2000[1973]: 5-6, 9-10). There were times when I would catch myself drifting away in a daydream while observing the same routines day in and day out – like



Figure 16: Christmas decoration at the Heart Intensive Care Unit (*Hjärtintensivvårdsavdelningen*). Photographs by Haris Agic, taken on a Christmas Eve.

ward rounds, for instance, or planning-sessions prior to ward rounds, or routine physical examinations, and taking the patient's anamnesis. Yet the reality of life wouldn't let itself be confined by routines. First and foremost, the human body is capricious and wayward enough to cause any kind of routinized clinical work a great deal of trouble. Second, technological equipment, so essential in clinical practice, proved often to be a real challenge to handle, thus disturbing the routines. And finally, individual and organizational factors allow free range for various kinds of surprises – both pleasant and unpleasant ones (Thelander 2001). Perhaps this is why the formalized routines in Heartlands always seem to aim for strictness, increased formality, and kind of a more commanding voice. And it is here, in these routines, in the midst of the daily practices, that I set my focus. I observed people in practice in order to get to understand how they *do* their world, the heart failure, and medical technology.

While working in the field requires embracing the tension between “reflection and immediacy” (Rabinow 2002: 38) a non-stop reflection upon what is observed is just plain impossible. “The scientific perspective on the world is hard to sustain”, says Rabinow, and I recognize myself in his statement. For me at least, it often required a great effort to zoom out enough in order to make sense of new experiences (Rabinow 2007[1977]: 38).

So what do you do once you set your foot in the field? Where do you start? How do you abide by your plan? After some initial moments of confusion, while roaming planlessly around the heart failure ward hallways, dressed in white, trying to see things, looking for the significance, the great discovery, I almost immediately experienced an immense feeling of powerlessness. The scope of the field turned out to be much greater and less controllable than I had ever imagined. Any attempt to steer things, to arrange the course of my observation, to plan in advance proved to be a waste of time. How do you gain control of the situation? This is what I kept asking myself, exhausted and drained by demanding efforts and discouraging failures. And then it became clear to me – you don't! You don't

because you are never isolated from the object of your study – that is the way of laboratory scientists and not of an anthropologist. Being in a hospital and doing participant observation means that you are part of the site and there is nothing you can control – nothing, apart from, at least to some extent, yourself. Yes, you can negotiate, insist and develop various strategies that would help you move around, get access, get answers, and comments. And at times you will succeed and you will have it your way! But this is always confined to the limits of what is given to you. You are in the midst of the given course of action! The field is framed in a certain way and you are bound to accept it! Not only is it your job to observe what is going on – you are also obliged to observe the rules of the field and to respect the given order of things. Such is the nature of your position, as you are only a guest. You are depending on what is given – people’s willingness, or lack of it, to provide you with assistance, answer your questions, think of you and let you in when something is up, to take your part when needed. So you don’t take control – you submissively play along. You just let your helm go and plunge into the current of the field. You adjust to the world and the people around you, and you keep on adjusting. It is like a never-ending improvisational jam-session to a harmony and rhythm you’ve never heard before. And the sooner you accept that everything is fieldwork, the sooner you can sing along with the capricious and explosive music of the field. Besides, being in control may not be so desirable after all. Too much control and strategic planning would leave no room for surprises. The unpredictable flow of the field functions as a superb and indispensable complement to the moments of more structured chats with informants, “Not dominating the terms of the interaction also had its advantages; not being in control enriched the fieldwork”, (Rabinow 2007[1977]: 94).

Keeping the fieldwork diary

Immediately upon arrival I started taking notes – about everything. Every little thing might count in trying to understand an environment and its people. Just as Rabinow asserted, “[N]ow that I was in the field, everything was fieldwork” (2007[1977]: 11). So I was eager not to let anything pass unnoticed. Thus I was taking notes of events as they took place. I was also eager to write down as much as possible about the contextual space of the ward – the corridors, chairs, whiteboards, computer screens, tables, windows, drapes, smells, colors, and sounds – again, every little thing might count. Even the briefest of the conversations might reveal an immense amount of facts that might be of importance⁴⁴. However, I soon realized that this wasn’t enough. Also, during certain episodes I found it less appropriate to take out my notebook – so I waited and tried to memorize. This is when I started taking notes in-between the events in order to catch the richness of things taking place. In general, there was not much room for reflection, for plunging into the field notes, making fair copies, and filling in the gaps of observations. I often imagined Malinowski, sitting in his hut late at night, writing in his field diary in the candle light, reflecting upon whatever took place during the day and planning for the best way to proceed with the field work the next day.

In the very beginning of my field work, when the sheer fire of my ambition kept me up and going, I would leave the hospital when observation hours were over and I would go home and immediately

⁴⁴ For instance, during a one-minute conversation with a nurse at the nurses’ station, besides the details of sentiment exchanged in our conversation and facts about the ward round and heart-surveillance equipment, I learned that this nurse was excited to talk to me; I learned that nurses look at the white bulletin board for information; that the nurses’ station is equipped with a computer; that this computer is positioned on the other side of the room; that there are two more computers on two desks positioned on opposite sides of the room. I also learned what the alarm sounds like when it’s mild. Small details like these are gathered routinely as the field work goes on and are to be found everywhere throughout my approximately one thousand pages of collected ethnographic field notes.

start working on my field diary until late at night – at times even until the break of dawn. This fire was extinguished, however, before long due to the fact that I would be far too worn-out to engage in the next day's participant observations properly. I couldn't let my field work suffer – so I ended up behind schedule with my diary instead. Thus, I tried to take notes as thoroughly as possible during the field work hours.

I devoted myself to close and meticulous observations of everyday practicalities of mending and living with sick hearts. Due to the reasons mentioned above, this proved to be considerably harder than I imagined. Instead of the imagined ideal of the serenity of Malinowski's hut and the meditateness of the candle light, field work in Heartlands required, at times, quickly taking refuge from the field – to a toilet, a terrace, or to one of the vacant rooms somewhere in the hospital – and writing the notes frenetically in order not to leave anything out. During one period I even had access to a post-operation exercise room that was vacant during the afternoons⁴⁵. Here, I would sneak in with a laptop which I kept in my locker and write down the notes in the dark – the dark was a deliberate choice because I didn't want to put myself on display through the big glass doors and draw attention, but I didn't want to be disturbed either. Yes, while I was doing this, interesting and important things might have taken place without me being able to take part in them – to take notes and experience. Not keeping up with the taking-notes-before-forgetting created an unrelenting and ever-present feeling of unease. The gap between the last observation and last clean copy of field-note scribbles grew wider as my field work progressed – and there was nothing I could do about it. At the same time, my frequent escapes from the epicenter to the shadows of the site in order to write down detailed accounts during observation hours imposed a risk of missing out on important things. And this was something I just had to learn to live with. During the last period of my nine months in the field I

⁴⁵ I was kindly provided with this space by one of my main informants – Lea the physiotherapist.

found myself devoting every second of my spare time to working on the diary – evenings, weekends, early mornings, and nights.

IV GLOBAL LOCALITY

Prior to entering the field I had a set of fair questions that were to be dealt with by identifying and collecting notes and sentiments on things taking place in Heartlands. Exiting the field I had a set of new ones aimed at understanding the collected notes and sentiments. This transformation of questions is part of the continuous process of *in situ* interpretation of the ethnographic data. Some of the old and new questions overlapped, some replaced the others, some remained the same and some were somewhat altered. During the processes of gathering and analyzing ethnographic data I was quite puzzled by the sudden shifts in my focus – at times I knew exactly what I was out to acquire; at other times I had no clue.

This study is based on ethnographic fieldwork, or more exactly, on participant observation. This is the only empirical method that allows the researcher to immerse him- or herself in everyday practices of the people studied – to observe the practices as they take place, and also to partake in some of them. At the same time, no matter how meticulous the ethnographer is and how thick his or her notes get, they still need to be placed in a broader, informative context. Here I hope to provide somewhat deeper and broader contextualization by an account of the *situatedness* of this setting, i.e. the way it is suspended on the historic axis as well as its relation to the outside world. By doing this I hope to avoid the trap of: a) the atemporal ethnographic present, b) the archaic idea of the purity of localness, and c) the danger of poor contextualization as the outset for the intended task of interpretation. Thus I will relate my field notes to the significance of its historical and sociocultural conditions.

The field work was conducted in a particular place during a particular period in time. Hence, the scope of this study is confined to

describing and analyzing the clinical practices of mending sick hearts in a modern university hospital, during a nine month period somewhere at the end of the third millennium's first decade⁴⁶. Consequently, conclusions found in this thesis can gain validity only in relation to this particular spatiotemporal nexus. The meaning and role of aspects including biomedicine, technology, the human body, the heart, and illness vary in shape and substance through time and space. Therefore it ought to be made clear that this study is based on particular encounters in a particular place during a particular period of time.

TRANSWESTERN CONNECTIONS

As this particular hospital is also a university hospital it is situated in the global web of biomedical science and practice. This means that doctors and nurses here are in continuous dialogue with their colleagues in other, usually Euro- and American-centered, and usually university hospitals – exchanging research findings, practical experiences, and new ideas. As I have already mentioned, this hospital provides undergraduate programs and is well known for its distinguished schooling for nearly all professions in health care. A medical degree earned at this school is currently ranked as one of the best in Sweden due to its distinguished theoretical approach that is intimately entwined with practice – the educational concept that is nowadays deployed as a model in numerous medical schools around the world. Moreover, this high-tech environment is intimately and firmly linked to the transnational Medical Industrial Complex (henceforth referred to as MIC), i.e. to the complex web of inventors, developers, manufacturers, merchants, distributors, and providers of health-related commodities and services. According to the Encyclopedia of Sociology, MIC “... refers to the health industry, which is composed of the multibillion-dollar congeries of enterprises including doctors, hospitals, nursing homes, insurance companies,

⁴⁶ An exact date is avoided due to the risk of revealing the identities of people studied.

drug manufacturers, hospital supply and equipment companies, real estate and construction businesses, health systems' consulting and accounting firms, and banks" (Estes 2010). No doubt, mechanical help-heart technology is by and large a part of this industry. All of the above renders the ventures of this particular hospital, in addition to being a considerable economic and political enterprise, also a significant factor in a global state of affairs. Its links to these powerful economical and political forces on a global scale are by no means indirect but are startlingly central and influential.

The oxymoron of neo-liberal socialist state

As Heartlands is inherently transwestern, in that it is suspended in the web of Western political and economical forces, some of its most central cultural values are shaped by this tension between the local and the global. Resembling Desjarlais' portrait of the Yolmo concept of the body as independent and interdependent all at once (1992), a particular Swedish take on the body rests on similar contradictory cultural values. Sweden has long been perceived as a unique 'third way' of social democracy fusing increasingly ever since the early 1990s state socialism with laissez-faire capitalism (Hirst and Thompson 2005[1996]). Although under the strong influence of the recent neo-liberal wave sweeping across the Western world, resulting in the neo-liberal government⁴⁷ winning the mandate of Swedish electorate in 2006, Swedes have remained relatively loyal and devoted to their deeply rooted belief in welfare. Yet this paradox of simultaneous interdependence and independence seems to go much further back in history. It is reflected in some of the most common idiomatic expressions in the Swedish language, revealing two contradictory cultural values: 1) One should do one's share (*Man ska dra sitt strå till stacken*); and 2) One should be self-reliant (*Man ska stå på egna ben*, or *man ska klara sig själv*). In the case of heart failure, then, the tension

⁴⁷ The Alliance for Sweden (*Alliansen*) led by the *Moderaterna* (self-entitled "workers party of today") believe in fostering free trade and open markets as a keystone of a modern welfare system.

between a patient's independency and interdependency, between his or her individual suffering, autonomy, and responsibility on the one hand and communal support and embrace on the other can be better understood when considered in its particular context of the historical and sociocultural conditions. As will be evident throughout this thesis⁴⁸, the downside of this particular tension between contradictory cultural values lies in that it puts a heavy strain on people suffering from severe heart illnesses by: a) demanding that they take responsibility for their condition; and b) demanding that they do their share in community life in spite of their limitations.

'Being there... and there'

The focus of my study is on understanding – from within – how patients and medical staff manage heart diseases daily at the hospital, and also in what ways this clinical everyday reality is connected to broader socio-cultural subject matters. The modern university hospital is a multi-professional environment with numerous different kinds of actors. It is situated in-between the local and the global. The complex hospital environment requires complex research methods. As it is in the commonness of everyday life that our thoughts and actions are shaped, provided meaning, and ultimately contested, the ethnographic method of participant observation seems indispensable for this enquiry. The main distinctive feature of participant observation is its adaptability to various settings, groups of people, and situations. Yet the challenges of the translocal character of settings such as the Heartlands remain.

Initially, while designing my field work, I often thought of Malinowski as he emphasized that “to live among the natives” was one of the crucial principles of proper field work. “[I]t must be”, Malinowski argued, “far enough away not to become a permanent milieu in which you live and from which you emerge at fixed hours only to ‘do the village’. It should not even be near enough to fly to at any moment for recreation.”, (Malinowski 2002[1922]: 6). This

⁴⁸ Especially in CHAPTER SIX – REINTEGRATION (pp 323).

principle means nothing but trouble for all of us interested in studying – anthropologically – our own societies. However, almost a century has passed since Malinowski wrote about how ethnographic work is to be done. I don't wish to imply that the anthropology and ethnographic methods in general have necessarily evolved, i.e. developed to the better. I simply wish to point out the fact that circumstances today are different than they were at the beginning of the last century.

The circumstances surrounding us, the global state of affairs, have been transformed. Our world is altered, imposing new challenges on all scientific disciplines concerned with human endeavor – and anthropology is no exception. What's more, ethnographic studies conducted far away from home no longer imply isolated settings and isolated peoples. In every corner of the world people are linked to the rest of the world: such is the nature of globalization. “[I]ncreasing interconnectedness in space” (Hannerz 2000[1996]: 8) opens up the world and turns what once was an “international” arena into a “transnational” one. In response, much ethnographic fieldwork has become multi-sited (Marcus 1995). Multi-sitedness, however, should not be confused with different localities simply being piled up; “... what current multilocal projects have in common is that they draw on some problem, some formulation of a topic, which is significantly *translocal*, not to be confined within some single place” (Hannerz 2003, emphasis in original). This ever-emerging translocality is forcing the traditional disciplines closer to each other, demanding an open-minded attitude towards multi-method tools and hence also towards an interdisciplinary approach. Ethnographic endeavor moves to the rhythm of the world – it has to! The traditional anthropological comparative methods are being challenged in “... a world in which no society is outside the global system, and in which it is increasingly artificial to speak of local perspectives in isolation from the global systems. Talk of us and them, their ways and our ways, is becoming increasingly archaic” (Fischer 1991: 526). These days, turning our ethnographic gaze

towards all parts of the world – including our own – goes without saying. People, places, cultures, and social structures are increasingly changing shape, taking on new meanings, joining various formations, and escaping others. This does not mean that comparison is being completely abolished from the anthropological palette; on the contrary, it has become more complex. Thus, it also requires a new approach. The copious current technological revolutions, massive movements of people all across the globe and transnational interconnectedness, pose the new challenge to the anthropological mission (Fischer 1991). The old principles requiring that people studied must be “far enough away” are exactly that – old.

I should make it clear right away that I do not wish to suggest that this book is a result of such a multi-site – or translocal – research. It is a study based on field work in a spatiotemporally clearly outlined setting and subject – the Heartlands and its practices. However, the subject matter that has caught my interest *is* translocal in its very essence. Its presence is not confined to the Heartlands but is scattered geographically. In other words, the practices of mending sick hearts with the aid of mechanical help-hearts exist at least: a) simultaneously (synchronically) – as diverse multiple manifestations of a single biomedical praxis; and b) as movement (diachronically) of people, things, processes, and ideas across various kinds of borders (Hannerz 2000[1996]). A particular branch of MIC specializing in development and distribution of mechanical help-hearts is situated in several competing businesses across the USA. Still, its influence resonates on a global scale, for instance in local-, often national-level, companies that focus on reselling and distributing mechanical help-hearts, and that can be found in nearly all Western countries. Local practices, as the ones that make up the focal unit of this study, cannot be correctly understood if their embeddedness in the global state of affairs is neglected.

The Heartisans of the Heartlands travel across the Atlantic to get educated and socialized in the art and culture of implanting

mechanical help-hearts inside human bodies⁴⁹. Others from abroad travel to the Heartlands for similar knowledge exchange. Heart doctors from all over the world gather at international conferences for another kind of knowledge and experience exchange. They move across borders, individually or in groups, to acquire and distribute knowledge, experience, recognition, and culture. Local practices travel, meet, interact, take turns, form networks, split up, follow, reinforce, contest, and mold each other. The ready-to-use mechanical hearts, while mainly manufactured and assembled in the USA, travel around the globe in various directions to end up inside someone's chest. Human hearts also cross national borders for the same purpose. Hence, the locality of the Heartlands should not be looked at as isolated from the reality of its translocality. Such a stance would contribute to serious decontextualization of the subject matter.

Several authors have emphasized the multiple character of the anthropological field in our contemporary world (Björklund 2001; Dahlén 1997; Hannerz 2000[1996]; Hannerz 2001; Wulff 1998). In his reflections on multi-site ethnography, Hannerz refers to the concept of 'polymorphous engagements', coined by Hugh Gusterson to describe an assemblage of ethnographic techniques for studying the macro-level global phenomena (Hannerz 2003: 212). Gusterson is the author of a well-known book entitled *Nuclear Rites: A Weapons Laboratory at the End of the Cold War* (1996), which is an ethnographic account of his research among the nuclear weapons scientists. The aim of this book was to increase our understanding of the moral dilemma of the nuclear weapons industry, policy-making, and politics. Although the main site of his research was a nuclear weapons laboratory⁵⁰, Gusterson holds that an understanding of the arms race that took place during the Cold War era requires that this complex process not be reduced to one or a few key sites (Gusterson 1996). Thus, he uses the local laboratory as a lens through which he can

⁴⁹ Actually, before they get to operate on humans, the surgeons practice on pigs and calves.

⁵⁰ Lawrence Livermore National Laboratory, USA.

understand national and global political processes. However, he does this by simultaneously keeping a keen eye on the dynamics of government policy-making, the relationship of the laboratory to its economical and political surroundings, the US-Soviet relations, a particular group of political scientists and policy makers that call themselves “realists”, and the whole antinuclear activist community in the US, especially a specific group of psychologists. It was not until one year after this book was published that he, in an article based on his experience of the field work at the nuclear weapons laboratory, coined the term ‘polymorphous engagement’. This term was clearly a retrospective attempt to understand his laboratory field work by a close look in the rear-view mirror:

Polymorphous engagement means interacting with informants across a number of dispersed sites, not just in local communities, and sometimes in virtual form; ... collecting data eclectically from a disparate array of sources in many different ways ... away from the fetishistic obsession with participant observation. [It also involves] formal interviews ... extensive reading of newspapers and official documents, and careful attention to popular culture ... As the communities we study disperse and link up across the globe... and as we try to match the emergence of global cultures with a global anthropology, we must develop new research strategies. If virtual space increasingly becomes a real space of social interaction then we will need virtual anthropologists to follow our subjects there (Gusterson 1997: 116).

Apart from attending one international transplantation congress that gathered hundreds of surgeons, anesthesiologists, nurses, biomedical researchers, and drug industry representatives, I did not follow the Heartisans around the world on their biomedical routes. Nor have I paid any visits to the manufacturers and distributors of the mechanical help-hearts. In that sense I cannot refer to my field work as multi-sited. There is no doubt that such ethnographic material would be of great importance for my research. However, for several,

mostly practical, reasons I abandoned the initial plans to actualize these potentialities⁵¹. Instead, I tried to embrace the translocal character of my field in its numerous *glocal* manifestations with the help of Gusterson's technique of polymorphous engagement. I took notes about local Heartisans on the move, their communication with other hospitals and with manufacturers of mechanical help-hearts; I listened to the stories they brought back from the international conferences, and I read scientific articles on hearts and mechanical help-hearts published in international medical journals. I also searched the information on the Internet to learn more about the manufacturers and distributors of these machines and about the ways they are portrayed in various media channels; I followed their annual reports and newsletters; I engaged in email correspondence with the Heartisans, and talked to visiting representatives of the MIC (who were often present during surgical procedures where their product was being implanted). In addition I scrutinized the reports, information, advertisement brochures, and films made by Heartisans and by the various manufacturers and distributors of mechanical help-hearts, read the newspapers and paid attention to other news channels. I searched through archives, took notes on patient journals; I skimmed through regulations and guidelines on clinical practice regarding the treatment of sick hearts and implantation of mechanical help-hearts (on national level but also in other countries), and I read various official documents and paid attention to popular culture.

I can, to a certain extent, see the value of the concept of polymorphous engagements in that it rests on the idea that the topic, a subject matter of the research, is polymorphous, flowing, and multifaceted – always changing shape. Yet the ethnographic techniques deployed, in my research and also in Gusterson's attempt

⁵¹ Because negotiations for access to the Heartlands took as long as nine months, and because the sensitive nature of these subject matters seems to require an immense number of approvals, green lights, okays, and backstage passes from too many different gatekeepers, I did not manage to design the intended multi-sited research to fit within the time-frame of my doctoral studies.

to grasp the complexity of the macro-level picture, seem to be more than merely different stages of one single method. The concept of polymorphous engagements, as described by Gusterson, doesn't really seem to manage to capture the entire multitude of this engagement. The ethnographic tools deployed here are not merely polymorphous but are in fact multiple – they are designed and deployed in harmony with the multiple character of the field. Diversity of sites calls for diversity of data collection methods. Moreover, I do not agree with Gusterson's critique of 'fetishistic obsession with participant observation' among the anthropologists nor do I agree with his assertion that participant observation is impossible in certain settings. I firmly believe that wherever there are humans there can and should be participant observation. The levels and strategies of participation and observation can vary due to the circumstances, but this does not render it impossible. In fact, I find it rather alarming to dismiss such a crucial scientific method as disposable 'fetishistic obsession' only because it is entering tougher contextual terrain for doing field work. After all, Gusterson's example of virtual anthropologists proves him wrong because it shows that participant observation is indeed possible – it only needs to be readjusted to the nature of the field. Rather than being thrown away and replaced, participant observation should be stretched, adjusted, and reinforced. It is, after all, through various forms of participating and observing that we experience, understand, and manage our lives. It is our way of being in the world. For this reason I have remained loyal to the participant observation, and I spent nine months of participating and observing in the Heartlands. Hence, my way of using polymorphous engagement as a research technique differed radically from Gusterson's model.

Apart from participant observation I also conducted informal and formal interviews, attended various meetings, corresponded with people by mail and telephone, and analyzed the various discourses. Still, there is no given structure for how these various techniques ought to be used or when and how they overlap, cohere, or collide with each other. During my field work in Heartlands, including the

preparations before entering the field and also including the subsequent process of analysis, I often found myself searching through a ‘disparate array of sources’ and experimenting with methods in the pursuit of my research aims. Often, I was guided more by gut feeling than by rigid analytical synthesis or reason. In other words, apart from the extensive period of meticulous participant observation, I often improvised on what ethnographic technique was the proper one for a given site, and what site was the proper one for a given situation. The picture became increasingly kaleidoscopic – the field was everywhere! The connectedness of these biomedical practices seemed to have no end. Since “everywhere” or “everything” is a bit too much, and might be a bit hard to record and to make sense of, I started changing the scope and density of the field as I went along – sorting, collecting, recollecting, sifting out, and discarding – in order to make the field doable. Still, and perhaps most important, due to my initial and infatuated interest in practices, my focus also remained loyal to practices in clinical work with sick hearts. With this I do not wish to say that the rest is less important. The ethnographic focus on local practices is just more in harmony with my research questions.

Ultimately, not only the method of data collection but also that of analysis shifts along with the volatile swaying of the field. Consequently, as the last stage of mechanical help-heart rite of passage aims for the patient’s reintegration (CHAPTER SIX – REINTEGRATION), it gives the whole treatment a completely new color in at least two aspects: a) it no longer takes place in the hospital alone, but between the hospital and the patient’s home, and b) it is inherent in its very goal that the patients turn to bodily discovering their new selves in a concrete context of everyday life. Two methodological implications follow from this. First, as much of this stage takes place outside the hospital, clinical practices can no longer be regarded as the richest source of data. Second, because reintegration and self-discovering as practical events are difficult to observe as they are essentially experiential, the patients’ own accounts

of these phenomena come into focus in CHAPTER SIX – REINTEGRATION. Thus, the study of clinical practice is spiked here with a stronger emphasis on phenomenological analysis of patients’ experience of their reintegration. This shift calls for another methodologically important question: how do we, from participant observation and interviews, get to people’s experience?

V

UNDERSTANDING, INTERPRETING, FEELING

Each day as I left Heartlands, I carried with me a big burden of painful emotional turbulence that would easily turn into a kind of numbness or vacuum. I do not write this to draw attention to myself or to angle for pity on my behalf. The people suffering from severe heart diseases, unbearable pain, uncertainty, and fear of dying are the ones worthy of compassion. My emotional burden was, perhaps, just the plain human response of caring. I got to leave home – most patients didn’t. As this was having a heavy impact on me I soon recognized that it would also affect my data gathering, interpretation, and analysis. In this section I will start by explicating some of the ‘technical’ keys I have used in analysis of ethnographic data. This will then be followed by critical discussion of the technical in anthropology with reference to the ethnographer’s subjectivity and emotions as well as to the paradoxical character of field work itself.

UNDERSTANDING THE FIELD NOTES

Technically, then, in order to answer my research questions I tried to look for the standardized daily routines in the field. What are the routinized practices? How are they done? When do they take place? How long do they last? In what context do they occur? What practices do they follow? What others do they precede? Which actors are involved in particular practices? Which of them are central? What artifacts, texts, and technologies are used? What is their role? How do people relate to other people? To artifacts? Texts? Machines? I also

asked about the action space; what do people say they can and cannot do and what do they in fact do? How do they do what they do? How do they talk about what they do? Furthermore, I tried to identify the ways in which people order and classify their worlds; is there a repeated pattern of dualisms to be discerned in the discourses and the practices of the Heartlands – such as objective/subjective, mind/body, normal/pathological, health/illness, rational/irrational? What can we learn from those binaries? In addition, I sought to map the metaphoric expressions that were in frequent use, in language as well as in practice – about the heart, the medicine, the body, the illness, and about the technology. The metaphorical expressions are treated here as a coded reflection of the encompassing cultural context, and are indispensable in any serious attempt to unlock and understand the meaning of our actions.

By paying close attention to the details of the ethnographic picture I have managed to gradually gather a large body of observational data containing detailed accounts of formalized practices and emic explanatory reflections which, when analyzed with the help of cultural analysis and ritual theory, began to reveal certain repeating patterns from which I could draw certain blueprints – the analytical condensation – signifying what might be called ‘the Heartisan way’. So I continued looking for the standardized daily routines, only this time instead of looking in the field, I was looking in the field notes.

The process of data analysis consists of systematic coding, auditing, interpreting, questioning, and intellectualizing of the content. For the first part of this process, organizing data, coding, and to a certain extent also analyzing, I used computer software specially designed for handling large amounts of qualitative data – Atlas.ti®. Hence, the total of one thousand and eighty-five pages of typed field notes was fed into this software, the main purpose of which was to help with storage, retrieval, and the coding process. Coding means literally marking the text in order to label particular parts of that text and attaching code words to particular stretches of data, which allows

the researcher to retrieve all instances in the data that share a code (Coffey, et al. 1996). The codes were grouped in code-families or code-groups. Analytic memoranda, or a comment, were attached to some coded segments of the text. I have organized the process of coding according to a search list, i.e. a list of certain concepts and phenomena specially designed to help map the main themes in the data as well as the relation between different themes, and also to discern the emerging patterns.

By drawing on ritual theory⁵² in my attempts to understand formalized practices that make the modern biomedical care, I was inexorably also bound to use cultural analysis as a primary analytical key “... necessary to understand the symptomatic and explanatory idioms that actors put into practice” (Reynolds-Whyte 1997: 4). As I take these practices to be primarily cultural processes, I turned to cultural analysis as a way of understanding them. By cultural analysis I mean a systematic probing of established views and taken-for-granted’s among the people in question. The principle premise of this is that all social groups partake in the formation of their history, culture, and identity – the facets that are continuously being embodied through the routines and practices of everyday life (Ehn and Löfgren 2001: 169) – and there is no reason to assume that medical staff and their patients are an exception.

First, with the help of a custom-designed search list I tried to map the social organization of the Heartlands, the underlying structures, processes, the actors, their status positions, roles and relations, spatial organization/spaces, artifacts, and machines. Furthermore, I looked for phenomena or objects that are associated by the peoples of Heartlands with strong sentimental values – symbols, myths, and legends. The main objective here was to capture cultural contexts and attitudes, emotional keynotes, and sentiments. The first, broad, search list consists of general concepts such as chaos and order, individual and collective, nature and culture, human and

⁵² For more detailed discussion of ritual theory see CHAPTER THREE – THEORETICAL FRAMEWORK (pp 121).

machine, emotions, life and death, time and space, private and public, power, gender, moral, prestige, work, and cosmology. The second, narrow, search list aimed at discerning the particularities of how various cultural conceptions are organized in relation to technology, the heart, truth, knowledge/uncertainty, action-space, responsibility/obligations, hope/trust, borders/transgression of borders, spaces in-between, humor, routines, and regularities/exceptions. I have tagged several hundreds of codes according to these search lists, which are then organized into ten large code-families. In order to make further sense of the ethnographic data I treated certain phenomena as cultural understandings and ideals. This way I could avoid the taken-for-granted's and understand what concepts of reality are brought about in practice.

Regarding the focus on rituals in particular, I tried to elicit from the data how the organization of ritual performance integrates people into the ritual action, what cultural ideas underlie ritual practice, and also what cultural ideas provide the interpretational logic for attribution of meaning to the misfortune of illness and to the technoscientific means of dealing with it.

I also looked at the particularities of Heartlands against the background of a broader global order of things. Therefore, I asked how homogenous transnational biomedicine (which tends to be Euro- and America-centered) is established, nourished, maintained, contested, and legitimated in practice on a local level. Consequently, I also asked how this particularity of the local heterogeneous biomedicine contributes to the organization of the global homogenous biomedicine.

Deployment of cultural analysis calls for the interpretative approach with an open character. In my case this means that, while remaining primarily rooted in the anthropological tradition, I make use of fields of disciplines such as sociology, history, history of ideas, and philosophy. I see the cultural perspective as a proper way of engaging in studies trying to understand human ventures. The challenge of contemporary scientific effort to bring together

traditional academic disciplines is in this thesis, I believe, acknowledged and approached with earnestness. My strategy is an answer to the Geertzian call for a particular kind of interdisciplinary approach – the one not proposing the total hybridization of – or total escape from – the separateness of traditional fields of study but rather demanding an openness where different disciplines embrace each other’s findings and try to make use of them. Geertz told us that social sciences and humanities would benefit from establishing a common language where different types of theories and concepts can be integrated “... in such a way that one can formulate meaningful propositions embodying findings now sequestered in separate fields of study” (Geertz 2000[1973]: 44). This way of looking at humanities and social science and its various fields resonates in more recent work of philosopher/ethnographer Annemarie Mol, who draws her inspiration not from “... a clear-cut discipline, but [from an] interdisciplinary, slightly undisciplined field” (Mol 2007[2002]: 22). Mol describes this field as a flow of theory moving across the boundaries of disciplines. It is exactly the egalitarianism of this undisciplined discipline that I turn to when I think of inter- and/or transdisciplinarity. There is no hierarchy – no stratum among the different fields of study. There is no periphery and no core of human beings. Geertz has warned us of such a science by pointing out that culture, psyche, society, and organism must not be converted into divided scientific levels that are absolute and self-sufficient in themselves (Geertz 2000[1973]: 41).

AND THE ANTHROPOLOGIST MADE THE ‘EMOTIONAL NOTE’

During my nine months of field work in a modern university hospital I was struck by the immediacy of the dark sides of human emotional existence, including suffering, pain, death, sadness, anxiety, uncertainty, ambiguity, loss, despair, danger, and chaos. Regardless of my initial methodological intentions, I inevitably found myself under the influence of my own emotional experience of the field. In this section, I wish to argue for *emotional notes* as an ethnographic tool that,

together with *field-* and *mental notes*⁵³ extends the anthropologists' reach where their diligence and curiosity alone cannot. I will also argue that, instead of jeopardizing the ethnographic endeavor, feeling the field adds to its validity. Ultimately, amidst the whirlwind of intense emotions such as those dominating the world of biomedical hospitals, instead of rejecting our emotional responses to the field and the people we study, we ought to embrace them as an often-neglected tool that can provide us with glimpses of things that are truly human.

I argue that emotional experience of the field and the people we study, especially the kind of emotional experience inherent in the fields of human misfortune and suffering, contains many insights essential to our understanding of social, cultural, and emotional dimensions of human life. Above all, in situations where a researcher feels the *heartquake*, or more exactly is honored with the unique privilege of a heartquake being shared in those moments of "understanding and bonding in human suffering" (Van Dongen 1998: 279), is when our understanding deepens beyond being merely intellectual.

Understanding the observed

Although necessary, the technical side of data analysis fell short of providing a more generic and comprehensive understanding of life in Heartlands. Whatever I managed to squeeze out from the field notes remained flat and square, forcing the colorful and vibrant life of Heartlands into a far too narrow frame. There was something missing.

The missing element in my analysis was more systematically ignored on my part than it was ever simply undetected or overlooked. It seems as if I was playing a game of denial in order to fit into the rigorous frames of established conventions for scientific analysis. In the meantime, whenever I was working with the field notes, I was brought back, quite vividly, to the field. Just as I was swallowed by the

⁵³ See pp 103-106.

avalanche of emotions – emotions of the people I studied but also my own emotions – during the field work, these emotions were easily evoked through the process of data analysis. Familiar bodily sensations – increased heart rate, a burning sensation on the surface of the skin, gasping for breath, anxiety often followed by extreme fatigue – appeared as I went through certain episodes. I recalled, while analyzing, coding, questioning, and intellectualizing; I recalled the sentiment, the feeling... the frustration, anger, grief, indifference, happiness, joy. I felt it all once again... and again. This made me wonder if this way of experiencing the field wasn't to some extent also what people of the Heartlands – the medical staff and the patients – feel in their dealing with vicious illnesses, uncertainty, and promising technologies? Isn't this the human way? Isn't there anything I can learn from my own emotional response to the things taking place in the field? Soon enough I realized that my emotional response affected my research more than I was initially willing to admit. Should I be worried, I wondered, that my *feeling the field* will contaminate the purity of scientific objectivity? Is it a threat to reason? In the end, how am I to legitimize my own emotional relation to my field as valid ethnographic data? But then again, how can a quality that is so central to human ways of being in the world be ignored as a factor polluting our knowledge? In the following I will discuss this, suggesting that feeling the field opens up yet another dimension of understanding human ways. Instead of being dismissed it can, and often should, be utilized as a tool in making sense of ever so intricate ethnographic data.

Emotional Notes

Field notes are the raw data in anthropological work – the ethnographic facts. Taken at face value, however, these facts might be deceiving. What they show is not equivalent with what they mean. Merely allowing the facts to speak for themselves would lead not to inference but to elusiveness. Hence, if any in-depth understanding of the cultural underpinnings particular to the field of study is desired,

the meaning of the facts must be extracted through the process of interpretation. This means linking and bringing into balance the "... abstract concepts with the immediately perceived realities of everyday life" (Rabinow 2007[1977]: 124).

Unsurprisingly, interpretation became the inevitable part of my attempts to understand the life in Heartlands. After all, the "facts of anthropology ... cannot be collected as if they were rocks, picked up and put into cartons and shipped home to be analyzed in the laboratory" (Rabinow 2007[1977]: 150). Each observable phenomenon is itself a product of culture. It is itself already an interpretation – it always has been – and is constantly in the process of becoming. What we encounter in the field as anthropologists is in the making. The raw data, on the other hand, i.e. the field notes, are but still shots of the observed flux of human life in a certain time and place. To make sense of the field notes we need to bring them back to life. Nevertheless, to blow life back into this static picture is in no way an easy task – especially if we strive to retain our scientific stance. In what follows I will try to get to the bottom of this problem and, based on my experience as an anthropologist in Heartlands, also present some suggestions regarding how these problems could be circumvented.

We anthropologists take notes, i.e. we scribble them down in a notebook. Sometimes, however, some events, faces, places, and spoken words stick in our memory – so we make *mental notes* (Rabinow 1977). Taking mental notes means that some things observed are for various reasons quite easy to remember, as if they were mental recordings of our observations. Mental notes form part of our overall field experience and are thus also influential on how we perceive, interpret, and analyze the conventional data – field notes. Then again, some things are heartfelt. They move us and cut deep into our being. They leave their mark, adding to the sediment of our embodied cultural selves. Therefore, they have a particular way of influencing our perception of the people we study and how we go about gathering, interpreting, and analyzing our data. These are

emotional notes. What sets emotional notes apart from the mental ones is that they are not only easy to remember – it turns out they might be rather hard to forget. Taking this into account, data gathered through the participant observation appears to be of three kinds:

1. Field notes
2. Mental notes
3. Emotional notes

As one of them is a formal and acknowledged form of ethnographic data, while the other two are still very informal and generally mistrusted, the final ratio among all three types of notes that are used in each research situation is somewhat of a riddle. It depends, perhaps, on several factors such as the deliberate individual preferences, tactics and choices of each ethnographer, his or her personality, background, and scientific environment. In most conventional ethnographic accounts, however, the reader is not readily invited into this part of research. Perhaps engaging in such discussion is as exhaustive and demanding (both for the writer and for the reader) as it is generally dismissed and stigmatized amongst the colleagues as irrelevant navel-gazing. Still, how can this part of our witnessing/understanding ever be open for critical scrutiny if we insist on systematically pushing it into the dark shadows of ethnographic research? Provided we really are able to detach ourselves from the objects of our studies and can limit ourselves to processing our data through the conventional filters, this should be no problem – although this situation would provide no room for the individual creativity of a researcher. But suppose we are not? Suppose we fail at being as “transcendent and clean” (Haraway 1997: 36) as the ideal would want us to be? Even worse, is there a risk of damaging this particular kind of data when we perform as ‘detached’ scientists – an ideal that belongs to the natural scientific paradigm? Or in a word, is our ethnographic detachment creating the ethnographic blind spot?

Researcher's subjectivity

In her analysis of Balinese construction of the self, Unni Wikan developed the concept of “double-anchoredness” (1990). In short, Balinese people view the self as anchored and continuously (re)created in two facets of a person – an inner self signified by the “heart” and an outer self referred to as “face” (Ibid: 104-106). Drawing on Wikan’s concept of double-anchoredness, anthropologist William Reddy emphasized the qualities of the situated cultural self, i.e. a part of our personality that most of the time stays hidden from our attention (Reddy 1999: 266; 267). This kind of “heart”, i.e. the situated cultural self, is made of a person’s embodied social, cultural, political, class, and gender background giving us the kind of “thought material” that is not always directly accessible. Only a deliberate reflection, Reddy argues, enables us to pay attention and, ultimately, gain awareness of this level of our personality that is rather uncanny, unpredictable, and often escapes the firm grasp of reason (Ibid: 269). In view of this argument, why we choose a certain subject to study, how we perceive it while observing it, and how we interpret and analyze the fruits of our observations depends to a large extent on this level of our personality. George Devereux argued that “The researcher’s character structure ... radically affects both his data and his conclusions” (1967a: 197). Ruth Behar also concurred by stressing that “*What happens within the observer* must be made known ... if the nature of what has been observed is to be understood ... in anthropology everything depends on the emotional and intellectual baggage the anthropologist takes on the voyage” (1996: 6, 8; italics in original). Clearly, these assertions are a call for a more reflexive approach in a more subjectivity-aware anthropology. In a word, as both our data and our way of analyzing it are filtered through our embodied “baggage”, i.e. our cultural and idiosyncratic selves, we need to be open about our own influence.

An allegory might help here. Let’s say we have a photo where everything appears bent or distorted in a circular motion. For those with a basic knowledge of the art of photography there is no doubt

that this particular photography speaks more about the character of the fish eye lens that was used when it was taken than of the 'truth' about the object or scene that is being portrayed. As long as this fact is taken into account, neither the photo nor the photographer can be accused of distorting the truth about the object/scene. The only thing distorted is the representation of the object/scene, with the aim of widening our experience of it by providing it with yet another dimension that is more stylistic and aesthetic. If, on the other hand, the photographer were to act as if no such lens was used, a photo might be regarded as a representation of truth about the object/scene and therefore also as a distortion of that truth. Similarly, anthropology does not claim to present the truth about people studied. It doesn't do so because it is not a natural, positivist science searching for the ultimate objectivity through 'exactness' by calculating and circumventing the 'probable errors' (La Barre 1967: vii). Provided that in anthropology there are as many lenses as there are anthropologists, in order to understand their ethnographic accounts we also need to understand the authors. This is why Behar and Devereux suggest that subjectivity needs to be brought out of the dark and woven into the ethnography.

Why is this, then, so hard to implement in ethnographic work? Is it because we are concerned that any revelation of our subjectivity will distort our 'scientific validity'? At the same time, how can we claim any scientific validity by simply avoiding and even discarding such an important aspect of our research? These questions obviously seem to lead back to the old dilemma of 'value-free social science', i.e. the conflict between the ambition for scientific objectivity and the assumed impediment of scientist's subjectivity (Hollis 1994). Behar asks this question: "How do you write subjectivity into ethnography in such a way that you can continue to call what you are doing ethnography?" (1996: 8, 9).

To what extent we refer to our field, mental or emotional notes while writing our ethnographies is perhaps not as much a matter of things actually taking place as it is of a tension between our personal

inclinations and the conventions of our academic environments, which are still under the significant pressure of the natural science paradigm. In a word, some ethnographers will, unless they don't feel anything at all, ignore, repress and/or deny whatever feelings they might experience in the field. Some others will be open about them and make themselves vulnerable to criticism by expanding them. Then again, some will sway somewhere between these polarities, tentative about what they should do with their emotional relations to their field. It appears that current conventions for doing ethnography fall short of providing the ethnographers with proper tools for dealing with their emotional notes. Instead, following the path of least resistance, it makes us shove our heads into the sand, pretending we either don't feel at all or, if we do, that we can easily put our emotions in brackets to ensure the sustained purity of our research. This needs to be changed.

It should perhaps be made clear that this call for emotional science is nothing of a novelty. Along with Devereux and Behar, mentioned above, philosopher James W. McAllister argued that emotions should no longer be considered to be antagonists of cognition and rationality and declares that "... reliance on emotional responses is a necessary condition for making sound inferences and decisions in many circumstances" (McAllister 2007: 22). Sociologist Simon J. Williams found the historical – ever since the dawn of the enlightenment and onwards – view on emotions as "... the very antithesis of the detached, scientific mind and the quest for objectivity, truth and wisdom" to be erroneous and argues that it should no longer be regarded as the "embodied enemy of disembodied reason" (Williams 1998: 748, 749). Williams also emphasized that emotions in fact are "... central to the 'effective deployment' of reason" (Williams 1998: 749). Furthermore, with reference to his study of *Isoma* healing rituals among Ndembu in central Africa, Turner argued that "Man's 'imaginative' and 'emotional' life is always and everywhere rich and complex", (1997[1969]: 3, my emphasis) adding that it is "... the whole person, not just the Ndembu

‘mind’, [that] is existentially involved in the life or death issues with which *Isoma* is concerned” (Ibid: 42,43). Clifford Geertz also joined this emotion-praising quire with words of warning, saying that human sentiments should not be reduced “to a shadow of the intellect” (2000[1973]: 355). Perhaps some of the strongest and most recent voices propagating for the epistemological value of researcher’s emotional experience in the field can be found in the edited volume *Emotions in the Field: Psychology and Anthropology of Fieldwork Experience* (Davies and Spencer 2010). Here, a group of prominent anthropologists criticize, from various perspectives, the concepts of detached ethnographer and objective science while at the same time praising the subjectivity of researcher’s emotional experience as indispensable for our understanding of human social, cultural and emotional life. However, the stigma of emotions in scientific work is deeply rooted and, as Behar expressed it, “... we still don’t know whether we want to give it a seminar room, a lecture hall, or just a closet we can air now and then” (1996: 16).

The Paradox of Field Work

The ethnographic field is by its very nature always rather weird and offbeat; it is almost real and far too real all at once. Or in other words, to an ethnographer a field is neither reality nor fantasy, but something in-between. It mocks the attempts at scientific objectivity and detachment, casts spells on our human selves, and seduces us into submission, while at the same time rejecting us as ‘strangers’ (Agar 1996) or as a temporary disturbance of the ordinary course of things (Devereux 1967b), a violation of the daily lives of the people we study (Crapanzano 2010), or as our own anthropological liminal phase (Jackson 2010). Katz Rothman described this sense of being caught by the whirlwind of her field in the following words:

Why was it so painful for me? For one thing, the women became so real to me; I came to know them, to care, to identify. Especially to identify. I had a baby at home. My second, born when I was 33

– too young in 1981, if not now, for amniocentesis. I was close, emotionally, and physically, to the pregnancy experience, to the terrible, urgent intimacy of that relationship (1986: 50).

Behar highlights the contradictory nature of field work by listing some of the stopping points in each ethnographic voyage, asserting that for each ethnographer a field work will at some point evoke senses including being out of place, wishing to blend in, feeling clueless about how to do it, being scared of observing too coldly, being scared of observing too raggedly, feeling enraged because of this cowardice, not knowing what to do with the insight that is always arriving a second too late, and feeling unable of writing anything while at the same time feeling a burning desire to write something (1996: 3). In doing field work we are expected to act as participants without forgetting to keep our eyes open. We should: "... get the 'native point of view', *pero por favor* without actually 'going native'" (Ibid: 5, italics in original). Ultimately, we should understand people's emotional lives, while at the same time renouncing our own emotions. This polarized symbiosis of incommensurabilities is the very paradox of ethnographic field work and especially of the method of participant observation. In the mean time, blinded by our search for the ideal of scientific validity we seem to have forgotten that anthropological research can't be forced to fit the normative model of natural sciences. Anthropology, in words of Behar "is the most fascinating, bizarre, disturbing, and necessary form of witnessing left to us" (Ibid: 5). It is a kind of science which, besides being performed, also is lived and felt. It is, therefore, always more organic than it is ever synthetic; always more analog than it is ever digital. It deserves to be recognized and treated accordingly if we are to get the most out of it.

DEEP ENCOUNTERS

... a feeling of injustice, even when it is associated with helplessness, can become a motivating sense of responsibility and a paralyzing sense of guilt can become a bridge to engagement.

(Smith and Kleinman 2010)

During my fieldwork in Heartlands I spent many hours talking to medical staff, patients, and sometimes also to their relatives. Somehow I felt, in spite of the pretence of my white coat, that I identified myself mostly with the patients. That depends, perhaps, on the fact that they were just as much outsiders in this context as I was. Compliant or not, they often didn't master the cultural codes of the hospital. The medical staff spent much time and effort in socializing them into the hospital culture and teaching them what is right and what is wrong and what the 'oughts', 'dos' and 'don'ts' are – until they reach the point of compliance and are ready to be integrated into Heartisan culture. Or perhaps I identified with the patients because of my background as a refugee. Specifically, the patients' crises brought by the disruption of their life narratives due to a life-threatening chronic illness rang a bell for me. I recalled my own fear of pain and death brought by the violence of war. I recalled shattered dreams. I recalled facing the end of life as I knew it. I once again saw myself enmeshed in an uninvited course of things, ending up in a new and unknown context full of uncertainties. I remember new hopes and expectations. I remembered being different and misunderstood, being ignored and being taken care of, being worried and feeling comforted. To me, life with the chronic illness of end-stage heart failure looked a lot like a life disrupted by war. The rescue found in mechanical help-hearts looked a lot like a rescue found in refuge. Should I have repressed this as an inappropriate and downright unscientific response? Is that what it really is?

As I became caught up in the intricate world of the power relationships, uncertainties, institutional frames, and a colorful diversity of vibrant human ways in the Heartlands I also found myself

deeply involved in understanding and bonding in human suffering. In the beginning, some of the patients turned out to be rather suspicious of me, not knowing quite where to place me. I wasn't a doctor, nor was I a nurse. Some of them stayed in the Heartlands for such a short period of time that I never got the chance to make real contact. Some, on the other hand, stayed longer and would still not talk to me in any other way than formally, briefly and somehow as if they wanted me to leave them alone – which I of course also did. But most of them initiated contact with me, greeted me with big smile as I entered their room, and showed uninhibited signs of affection, warmth, friendliness, and appreciation. There were those who would confess to me, who would talk to me for hours and let me in, very close to the most private corners of their hearts, those who would hold my hand and let their tears pour out in cascades. This was the area of my strongest emotional involvement. This I could not ignore.

Before the field work, I was well aware of the dying and human suffering that I was going to encounter. Was I really ready for this? Will I ever be? No, I wasn't! And no, I won't! I remember urging my supervisors to have a counselor on stand-by for me, in case I were to feel the need for debriefing while in the field. And I was right – my time in Heartlands was one of the toughest things I've ever deliberately gotten absorbed into. The image of the man I shook hands with on my very first day in Heartlands still haunts me – the next morning, when I came back to the ward, I was told that he had died during the night. This was my welcome to the field – and this wasn't the last time I encountered death while in the Heartlands.

Perhaps just as hard (if not harder) to handle as exposure to people dying was all the suffering I came to witness during my time in Heartlands. These daily encounters with people in pain, people who seemed lost, became a constant reminder of how precious and how fragile life is. I can't say I felt their pain – no one really can! But I most certainly felt mine, raging through my whole body. I felt a huge lump of *nothing* growing inside me as if it threatened to burst my chest wide open. Often, while not in the field, I found myself unable to pay

attention to whatever I was doing – talking to a friend or watching a movie, for example. I just drifted away as I pondered the hardships those I left behind at the hospital had to endure. While breaking a sweat on the treadmill running for that extra mile, I would look at the little red lamp on the display showing my heart rate – and next thing you know I would find myself gasping for breath, haunted by uninvited images from the Heartlands. Prior to my field work experience I was not bothered by these things. Of course, I knew that some people are less fortunate than others regarding their health and that there are a whole lot of heartbreaking stories taking place in the world. But I was never *this* aware of it. And, I admit, I wasn't so prone to intentionally engaging in any deeper thinking about these things. I was never exposed to this side of being human, not this close and vividly to those in despair. The images of these people became my shadow, following me everywhere even as I gathered with my friends over a cup of coffee, or attended family dinners.

Sometimes I would start talking about these people and the suffering they go through. Sometimes my friends and family would show interest and listen carefully. Yet, just as easily as the topics are avoided, so can also the people identified with certain topics be. I knew that these subject matters are heavy and could easily spoil the good atmosphere of any gathering. Therefore, I refrained from talking too much about this. I didn't want to burden the people around me. Nor did I want to commit social suicide. So I wrote instead! And this also proved to be a pretty good therapy. This was, among other things, the kind of thing that helped me make it through the whole nine months. I would put down almost anything on paper, never thinking of what specific significance this and that would have for the research – I just poured my guts out. Anger, frustration, anxiety, fear, melancholy, warmth, care, concern – I just put them down on paper or typed them onto the computer screen. And each time it felt really good. I could feel a sense of relief grow with each word written, abating the *nothing*. However, I wasn't writing merely for therapeutic purposes. My feeling things, and my putting these feelings into words

and phrases, was already having a huge impact on the way I perceived and interpreted field notes. These two reasons were more than enough for me to recognize that these emotions ought to be embraced instead of ignored or repressed.

Seeing yourself in the 'other'

As I entered the room, I also felt that I was about to cry. This feeling, as I recall it, came over me as soon as I stepped into the dimly lit room, and is perhaps connected to the importance and awe ascribed to birthing and witnessing the seemingly consecrated practice of birthing.

(Jonvallen 2010: 154)

I have already mentioned the urge I felt to talk about these heavy subjects with my friends and family. Yet it was not always that easy. At the same time, many of the daily life situations would require that I explain myself to others – to explain why I might have been quiet at the dinner table, absent from a get-together, easily provoked, or touchier than usual. People around me would wonder what the matter was and I would feel that I must explain myself, to justify my behavior. However, once spelled out, these things would need to be negotiated. “It’s getting to you”, “It’s all in your head”, “Let’s not go into that now”, “You need to relax”, or, worse, no response at all, were the most usual reactions to my whining. There was a paradox in this situation. Refraining from these negotiations left me short of desired recognition and empathy. Engaging in them made me unbearable to be around. This was one of those moments when I felt what I thus far had only have read about in the scientific literature, describing how chronically ill people need to negotiate their experience of suffering on a daily basis – particularly the ones whose illness is not visible to others (Masana 2010). My own experience, my emotional notes, have brought me closer to understanding the patients and the torment imposed on them by this situation.

The sensibilities I learned through my emotional experience were, no doubt, strongest while still in the making, i.e. while I was still *in* the field – still among them. I remember one of the strongest

examples of this emotional learning during an episode in which I *felt* the warmth of a man's hand as it stretched out to gently grab hold of mine only seconds before his chest was about to be split open – seconds during which the 'see you later' and 'good bye forever' sentiments are both paradoxically expressed in a squeak of cacophonous synchrony, a friction between forceful emotion and passionate reason caused by the 'no warrant of success' character of any open-heart surgical procedure. I *felt* the gaze of his scared tear-filled eyes, and *felt* the sound of his voice saying, "Haris, I sincerely hope that you will get all that you need from all of this". It was a kind of inter-human emotional experience that provides the kind of understanding that intellect alone simply cannot. What's more, this emotional whirlwind was additionally boosted as it became clear that to me the hours to come meant staying focused, taking notes, and paying attention to details. But to this frail human being holding my hand, it meant a certain probability of finitude and uncertain probability of salvation.

And there we were, holding hands, looking at one another, sharing the moment – possibly his last – and yet belonging to two different worlds. In sharing this moment, the absolute difference between our destinies brought an acute and unmistakably emotional awareness of mortality to me. Desjarlais tells us: "One learns of another way of being and feeling through contrast, noting the differences that make a difference" (1992: 19). In similar fashion, this particular encounter with another human's finitude enhanced my sense of my own vitality in a rather absurd way. And that is when this absurdity of my vigor in the face of another human's misfortune rendered his destiny even more absurd and unjust to me. My body was positioned upright, his was lying down; I was looking down on him, he was looking up; I smelled of early morning shower, he smelled of hospital and alcohol-based hand cleaner; I had curiosity in my eyes, he had fear and doubt in his; I was frightened by his, was he encouraged by mine? It was clear to me that the truth of any 'fact' of life is always in the eye of the beholder. Therefore, I realized that

people, in order to truly understand each other, need to learn to read the reflections of each other's 'facts' of life, mirrored in each other's eyes, bodies and practices. In eyes of this man I saw a bizarre image of myself – 'a difference that makes a difference' *par excellence*. The ethnographer's emotional experience contains many insights essential to our understanding of social, cultural, and emotional dimensions of human life. What a waste to have such a power neglected.

Fear, resistance, will, despair, hope – these sides of being human can never really be grasped solely through logical thinking and analysis, at least not in the same way as when a human is immersed in them. I didn't write this episode down. It is absent from my field notes. And yet I can tell it by heart, in great detail, any time. I have seen it repeating in my head so many times now, both intentionally and unintentionally. There are plenty more of such heartfelt episodes that ended up as *emotional notes*. I know them all for a fact. And I don't think I can ever forget any of them. But even more importantly, I know these episodes *by heart*. The trick now is to pass on this sentiment to others, to evoke the readers' emotional responses by surrendering to a certain style of writing that allows them to "get it at the gut level" (Rothman 1986). It seems as if "We lack the language to articulate what takes place when we are in fact at work. There seems to be a genre missing" (Geertz 1995: 44). Doubting, nevertheless, that my writing skills could ever live up to these expectations I will make an honest attempt and still try not to turn this thesis into an instance of self-absorbed attempt at sensationalism. Be that as it may, I believe that it is unavoidable that the very fabric of this text is woven by the ways in which I have felt the field.

SUMMARY

An emotional note is not easily forgotten. How could it be? My experience of the dark sides of Heartlands proved to be rather painful, intense, and overpowering. There was no way of avoiding it. It lurked around each corner, in every room, in every encounter with anything and with anyone. At the same time, I believe that it is not

possible, and neither would it be desirable, for an ethnographer to detach him- or herself from the field until he or she felt safe from feeling. At the risk of opening myself up to charges of engaging in sensational journalism rather than serious scientific research, I argue that emotionally engaging deep encounters provide insights into those areas of human life that cannot be grasped by reason alone. Unless we promote a complete expulsion of the 'feeling' kind of ethnographers from the ethnographic community, we should at least consider giving them enough space so that they can make their unique contributions to the vast body of ethnographic knowledge about human life. Otherwise we might just end up with an armful of neatly made ethnographies behind which graveyards of disclaimed emotions lay hidden. Perhaps we can always try to hide our feelings, but we can never hide from them.

Still, an ethnographer is but a temporary visitor in his or her field, soon to be released from its burdening emotional grip. People spending their lives working in hospitals don't see their workplaces as 'the field'. Most of them are going to spend a significant part of their lives there. Perhaps it is a matter of time – medical staff, for instance, cannot afford to surrender to the emotional whirlwinds because sooner or later it would take its toll. Neither do the patients see the hospital as 'the field', nor can they afford surrendering to their emotions – with the help of the medical staff they develop strategies to manage their emotions in order to cope with torment and uncertainty. Ethnographers are in no way an exception to this, although the extensive taking of emotional notes as suggested here might eventually leave us bloated and unprotected. And this is exactly what happened to me. During the last three months 'in the field' my frequent nightmares about my field work became unbearable. I just felt that I had had about all I could take. It was time to leave the field. Nevertheless, in escaping the field I must not forget why I went there in the first place. Asking myself *how* I do anthropology, I often found myself answering another question of *why* I do anthropology, and vice versa. It didn't take long until I realized how intimately intertwined

these two perspectives are for me – sentiment and reason, “heart” and “face”, the emotional and technical hand in hand. The following assertion provides a rather precise answer to both questions, “The point is to make a difference in the world, to cast our lot for some ways of life and not others. To do that, one must be in the action, be finite and dirty, not transcendent and clean” (Haraway 1997: 36).

VI ETHICAL CONSIDERATIONS

Prior to initiating contact with the gatekeepers I submitted an application for approval from the Regional Ethical Committee. The application was examined and approved. Brief and comprehensible written information about the planned research was sent to all the wards and care units before the field work. I have also presented myself and my research formally at several staff meetings during my first days in the field.

Regarding the patients, however, the situation was not as simple. In collaboration with doctors at the hospital, I prepared written information specially designed for the patients. The information was written in two parts, in two separate documents. *Written information, part I* speaks to all the patients at the Heartlands, regardless of the type of their diagnosis and planned treatment, including the outpatient clinic patients. *Written information, part II* addressed the end-stage heart failure patients who were waiting for, undergoing, or recovering from the implantation of a mechanical help-heart. The purpose of dividing the information was to avoid imposing anxiety onto the patients with heart disease who were not potential candidates for mechanical help-hearts. However, even with neat information documents in my hands, handing them out prior to observing sometimes proved impossible. Some of the patients were unconscious, others were heavily sedated; sometimes the situation at hand didn't allow for me to present myself properly to the patient nor to hand out the written information documents; sometimes the

medical staff would present me as their “colleague”, leaving no room for me to correct this error during the particular situation. Thus, I found myself coping with the tricky circumstances the best way I could. I have managed to get a signed informed consent from all the patients that I had engaged in somewhat deeper conversations with, and also from the ones I had ‘caught’ on tape, and the *one* that I have video-filmed during a bypass surgery. Regarding the rest of the patients I was at all times trying to make sure that it was generally known who I was and what my role was in the Heartlands, even if that wasn’t very easy. I have observed the Swedish Research Council’s ethical principles and guidelines for research in the humanities and social sciences, the primary criterion of which is that the individuals who partake in the study must not be harmed. They should be provided with clear and sufficient information about the study; they should consent before being included in the study, and they should know that they have the freedom to end their participation at any time and without any explanation. All gathered data, field notes, sound- and video recordings, and transcripts are at all times stored confidentially. The data is only used for the purposes of research.

CHAPTER THREE – THEORETICAL FRAMEWORK

[T]he age of grand theories – thus, theories that seek to explain everything – is over ... any one theory will hardly suffice to account for the complexity of the phenomena. In modern scholarly practice of the study of ritual, one will therefore probably always need to refer to more than one theory.

(Kreinath, et al. 2006: xxiii)

Mechanical help-heart implantation is in many ways an extraordinary practice. It is formalized, imbued with structured repetitiveness, loaded with symbolism, acknowledged as exceptionally important, enacted through bodily performance, instrumentally significant – while at the same time it is aesthetic and theatrically expressive. These qualities reminded me of all those rituals of tribal societies that I came to know through anthropology. Therefore it came as no surprise when I, during my data analysis, found it to be of great help to think of these modern high-tech biomedical practices as rituals.

The etymological roots of ritual can be traced to Latin *ritus*, a word that, in turn, is closely related to Greek *arithmos* (a-rit-hmos) meaning “number” (Encyclopaedia-Britannica 2010a). Another word derived from *arithmos* is the English “arithmetic”, from Greek *arithmetikē* which is composed of *arithmos* and *tekhne* meaning “art of counting” (G&C 1913; OxfordUniversityPress 2010). The Online Etymology Dictionary suggests that the Latin term *ritus* has Proto-Indo-European base **re(i)* meaning “to count” or “number” (Harper 2008). The same dictionary points to Old English term *rim* which means “number”. Encarta World English Dictionary suggests Indo-European roots meaning “fit together” (Microsoft 2009) or “to join” alternatively “to fit accordingly” (LoveToKnow 2010). There is also Sanskrit word *rīti* meaning “a stream”, “a running”, “way”, “manner”. *Ri* meaning “to flow” is also mentioned as a possible root (G&C 1913; Ultralingua 2010). A closely related Indo-European root *rheein*

meaning “to flow” is also the origin of the concept of “rhythm”, a noun denoting a “strong, regular repeated pattern of movement or sound” or “a regularly recurring sequence of events or processes” (OxfordUniversityPress 2010) .

These traces of the origin of the word ritual bring to mind contemporary idiomatic expressions such as “to perform a number”: as, for instance, a magic trick, a song or a dance (a dance number). These English idioms have their equivalent counterparts in Swedish: *att uppträda med ett dansnummer* (meaning “to perform a dance number”) or *sångnummer* (“song number”). Hence, ritual seems to be essentially about imposing “order” through performance or “ordering”.

Given that mechanical help-heart implantation practices are transitional and transformative processes, a particular model of ritual taken from van Gennep (1960[1908]) and Turner (1997[1969]) will be used: *rites of passage*. Before we go into further details of rites of passage I will give a more or less comprehensive overview of ritual theory in general, explain some of the concepts central to ritual theory and of relevance for this study, and finally position my own approach in relation to this vast body of knowledge.

I RITUAL THEORY

My interest in ritual studies comes from my anthropological background. What I always found particularly interesting were the unique ways in which rituals assemble and engage people. Being both extraordinary and ordinary at the same time⁵⁴, rituals are inherently contradictive. They enjoy certain status amongst the practices and are always surrounded by an aura of importance. Why a certain ritual is organized and performed in a certain way is an essential empirical

⁵⁴ While being rather bizarre forms of practice, unlike our everyday actions, rituals are nevertheless some of the most universal types of human behaviour, documented in all known cultures throughout history.

question which can bring us closer to understanding the role that these particular practices have in human life.

Fascinating as it is, the subject of ritual (or rite or ceremony⁵⁵) exists amidst vast variety of academic traditions. It is a domain of human life that cuts across the frames of intellectual traditions and is, thus, inherently transdisciplinary. Sociologists, sociologists of religion, historians of religion, historians of ideas, philosophers, psychoanalysts, anthropologists and many others have all been interested in rituals, often describing these peculiar practices as windows into the core of the social and cultural life.

Throughout the 19th and 20th centuries the concept of ritual was nearly ubiquitous in all sciences dealing with collective human life. It has been said that rites reveal the essentials of shared belief in a certain society (Malinowski 2002[1922]: 392). Ritual was also described as an art form that gathers and organizes some of the most important cultural themes, such as death, masculinity, pride, and loss (Geertz 2000[1973]: 443, 444). Ultimately, it was said that rituals disclose deeply sedimented values of the group (Turner 1997[1969]) and that rituals are "... the key to an understanding of the essential constitution of human societies" (Wilson 1954a: 240). However, as all the things that claim to deserve a place under the umbrella of 'ritual' compose together a field too vast to be useful at all I will carve out a portion to suit my purposes here.

Ritual – particular kind of practice

I see rituals as particular kinds of practices: *practices* because they need to be put in practice in order to take place at all; *particular* because they do not correspond to all practices. Obviously, any proper ritual theory is, in one way or another, intimately linked to some kind of a practice theory. Hence, I will explicate here what understanding of practice I

⁵⁵ A more comprehensive discussion of these terms and the ways they relate to one another is presented in detail below (pp 157-158). For now, it should suffice with declaration that they will be used randomly and interchangeably with no reference to any kind of differentiation between them.

draw from when I speak of rituals. Generally, I draw here from the idea that “reality doesn’t precede practices but is a part of them”, (Mol 2007[2002]). Garfinkel once wrote also that peoples’ understanding of their world gains its comprehensible and observable form in and through their practices emphasizing that practices “... are carried on under the auspices of, and are made to happen as events in, the same ordinary affairs that in organizing they describe” (1967: 1). Butler argued, in similar fashion, that the boundary between sex and gender is an illusion – sex is constructed through social *performance* of one’s gender and sexuality (1990; 2005). Bourdieu stressed that it is our aptitude to get constructed by the world, i.e. to ‘em-body’ the “structures of the world”, that facilitate our ability to construct the world we inhabit (1977: 89). Latour and Woolgar showed that scientific knowledge is socially constructed in and through concrete practices as routinized parts of the process by which scientists make sense of their observations (1979[1986]: 32). Haraway discussed the conception of doing worlds, i.e. “worlding”, as active human participation in construction of reality through practices (Gane 2006). All these concepts of doing, worlding, performing etc don’t always necessarily point to the same referent (action, practice, behavior) or to the same reference (such as problem-solving, goal-achieving construction of self, identity-making, meaning-making, reinforcing the social oughts). In other words, they are related but not identical. I will not, in this study, make any attempts to try to get to the bottom of this issue. Nevertheless, I believe, adopting Reckwitz’s line of reasoning, that what these concepts have in common can be synthesized into quite a useful definition of practice as a “... routinized way in which bodies are moved, objects are handled, subjects are treated, things are described and the world is understood” (2002: 250). This is the kind of understanding of practice that I assume constitutes rituals.

Bonds that knit us to people around us, to our fluid and dynamic sociocultural fields of existence, are tense and vibrant. They constitute the core of social order and are multiple and diverse. They *are* our

relations to others – relations that are sometimes vivid and sometimes hidden, idiosyncratic and/or conventional. Nevertheless, due to their tense quality they always seem to be in need of maintenance with a lubricant that will provide them with elasticity, saving them from splitting and falling to pieces. This preservation is practice – things we do in order to generate the sense of what it *means* to be human. What it means to be human, who we are and what the world we live in is all about is something we actively bring forward and extract in and through practices – sometimes deliberately and most times not fully so. It is through our inter-subjective practices that we synthesize the dialectical tensions between immanence and transcendence, between particularities of our individual selves and generalities of societal norms expressed through public discourse; it is here that we actively conquer the sense of ourselves, each other, and the world we live in.

What is it, more exactly, that makes certain practices ritual? Overall, ritual scholars refer to three major qualities that seem to be inherent to ritual:

1. Instrumentality – ritual as means to bring about change
2. Communication – aesthetic qualities of ritual performance sending out certain messages to its audience (which most often consists of the performers themselves)
3. Formality – ritual as way of ordering practices so as to reflect the norms and values deeply rooted in the culture of the people performing the ritual.

In the next section, I will be taking a closer look into these three main features of ritual.

MAIN FEATURES OF RITUAL

Instrumentality

A quick look at the ways ritual has been discussed in the past reveals three qualities that seem to be at the core of any theoretical discussion of ritual, namely *instrumentality*, *communication* and *formality*. Mainstream theoretical discourse about ritual, however, has primarily been directed towards various divergences that need to be brought

together, changes that need to be dealt with, and/or imbalances that need to be leveled – all of which render ritual as utterly instrumental in character⁵⁶. Among the Azande, rituals were explicitly described as instruments to put the witchcraft into effect, to counteract the threat of witchcraft and/or to find out details about the witchcraft being used (Evans-Pritchard 1976[1937]). The Ndembu used rituals to, among other things, solve the tension that the paradox of twinship causes in the community's understanding of reproduction (1997[1969]). The Yolmo people from Helambu, Nepal, use rituals to “throw” out the malevolent spirits and thereby to get rid of the harm from the body (Desjarlais 1992). A wide variety of changes and/or divergences in people's lives are, among different peoples, experienced as disruption of the ordinary course of things in individual and/or collective lives. Rituals help to deal with crisis such as rites of passage or annual or seasonal ceremonies (van Gennep 1960[1908]). Ultimately, individual and/or social lives are permeated by relations and circumstances that are recognized as tense or bumpy, rugged, irregularities or inequalities that need to be leveled out. Thus, ‘face-work’, for instance, allows people to reduce the underlying frictions in their daily encounters by temporarily putting the ‘bumps’ and tensions aside (Goffman 2003[1955]).

Dualism of instrumentality – explicit and implicit purposes of rituals

Evidently, ritual is often depicted primarily as instrumental, i.e. a means to an end. The end it seeks to reach is, however, of a rather complex character. Turner describes this end as two-sided: one explicit (emic – as explained by the natives) and one implicit (etic – as interpreted through symbols⁵⁷). So, while the emic purpose of *Isoma* ritual is to counteract misfortune, the etic one is to reveal the

⁵⁶ Ritual has also been portrayed in mainstream public discourse and popular culture as primarily instrumental – for instance, rituals within Catholic Christianity are often featured as instruments for eviction of evil spirits from a possessed person or a place.

⁵⁷ Nevertheless, Desjarlais tells us that if we are to make sense of a culture, a semiotic model of analysis alone will not suffice (pp 134).

collective concern for marital institution and maintenance of societal reproduction (1997[1969]). Similar thinking about the twofold purpose of ritual is present in other analyses of ritual. Durkheim highlighted that the emic purpose of rituals is worship of gods while the etic one is imposing and reinforcing social order (1915). Gods are but symbolic expressions of society, according to Durkheim, and the ultimate goal of ritual worship of gods is to keep the society from falling apart (Ibid: 346). By asserting that reality, which he believes to be the foundation of any religious experience, doesn't necessarily conform objectively to the ideas that believers have, Durkheim suggests that the real aim of the ritual is hidden behind the make-believe curtain of the sacred (Ibid: 417). He regarded rituals as dynamic aspects of religious beliefs, i.e. determined modes of action that are secondary in relation to beliefs, merely expressing them (Durkheim 1915). In other words, for Durkheim rituals are enactments of religious beliefs. His understanding echoes the Cartesian mind–body dualism⁵⁸. Thus, rituals are collectively attended to by people who are just as aware of them as they are of each other and of their common descent. They don't see, on the other hand, the particularities of ritual itself but the 'real' effect that ritual has. Worshipers have a clear purpose with their rituals. To aborigines, the purpose of ritual is to respect and abide by their tradition, the authority of which is regarded as the very source of the ritual power: "Men celebrate it to remain faithful to the past" (Ibid: 370). What they are not aware of, according to Durkheim, is that there is yet another actor present here, omnipotent and godlike in its very essence – the society.

Obviously, Durkheim assumes a functionalist approach where rituals play a mechanical part in societal maintenance. He ascribes an instrumental quality to rituals that consists of their ability to express and reproduce already established world views. Although the explanation aborigines themselves provide reveals a more complex purpose of ritual activity than merely the worship of gods, it is still

⁵⁸ Thought (religion) on the one hand and action (ritual) on the other.

oriented towards the past⁵⁹ and seems to bear no intentional connection with societal continuation into the future as its explicit goal. So what Durkheim is implying is that the make-believe of ritual and religion works as a blindfold hindering the worshipers from seeing their real god – the society – as if to keep them from harming it.

Durkheim looks for rituals on the macro-level of social life. Thus, he views rituals as collective religious practices, the ultimate function of which is to reproduce the moral (devotion and loyalty to tradition), social (affiliation to community) and material (physically embodying the ties to the community through bodily performance of ritual) glue keeping the society together. What Durkheim asserts is that the main purpose of these formal collective acts is not to please gods but to reinstall the sense of community by expressing it through articulation and performance (Ibid: 226). Religion and ritual are but vehicles for continuation of society, i.e. the instruments for awakening of collective consciousness which also are their very source. The believers worship their gods unaware of the fact that the practice of worship is a way of recreating and nourishing the collective consciousness – the very fundament of society (Ibid: 346).

Tendencies to describe the instrumental character of ritual should be no surprise as most theorists were, and many still are, interested in revealing the ultimate purpose of ritual – a question that provides the affirmative answer to a question: ‘Is ritual essentially purposive?’. In fact, the ‘purposive’ characteristic of ritual seems at times to be so certain that even the deliberateness and intentional goal-orientation among actors seems not always to be required. Or, at least, they are ascribed to ‘something’ else, i.e. ritual’s implicit purpose. For instance, we use various rituals to manage our everyday social interaction regardless of whether we intend to or not (Goffman 2003[1955]). The majority of classical ritual theorists seem to have accepted this postulate of ritual as essentially instrumental. Still the perspectives remain manifold, to say the least, mainly depending on the level on

⁵⁹ More on the reverence of ancestry below (pp 155-156).

which different scholars approach ritual practices and also on which focal units of analysis they choose.

Different intellectual traditions have been interested in different 'levels' of human life where these rituals are performed. Goffman, in contrast to Durkheim's macro-level analysis, was looking for ritual elements in micro-levels of social life, in everyday social encounters. 'Face-work' enabled social interaction, which in turn is essential for any kind of social order to exist. Here, the ritual codes of conduct are establishing a temporary make-believe drama in which the idiosyncratic obstacles are put in brackets in order to make interaction possible. Goffman asserts that these ritual codes are the condition rather than the goal of interaction, implying that the ritual is basically inherent and habitual (2003[1955]: 8). The explicit function of ritual, according to Goffman, is interaction. At the same time, the function of interaction is a blindfold hindering people from directly recognizing and reflecting upon the ritual elements of their actions – as if to keep them from disturbing them.

Most scholars' attention was, however, directed towards the *implicit* instrumentality of rituals, i.e. not what they do according to the natives but what they do according to scientific analysis and theoretical interpretation. Malinowski was, along with Durkheim, another spokesperson for the macro-level functional character of ritual behavior. He argued that rituals are normative in that they hold the power of continuous fortification of custom – what he calls "inertia of custom" – which is, according to him, the elementary law of sociology (2002[1922]: 326-28). Under the influence of Malinowski, anthropologist Evans-Pritchard took over the torch of British functionalism as he emphasized ritual as an (implicit) instrument for alleviating people's anxiety about things that are beyond the reach of human agency; witchcraft and oracles were used to settle conflicts among the members of Azande society⁶⁰ (Evans-Pritchard 1976[1937]). Another branch of scholars echoing functionalist stance

⁶⁰ Whereas according to the explicit purpose, these rituals were used to handle the witchcraft both as a threat and as a resource.

was the Culture and Personality School with Ruth Benedict as perhaps most influential representative. In her book *Patterns of Culture* (1989[1934]) she explained the instrumental function of rituals, in a fashion quite similar to that of Evans-Pritchard, as a way to cope with unease brought by those parts of human life that are beyond human control, such as: death, illness, procreation, floods, and draughts (Benedict 1989[1934]). All in all, rituals were described as instruments the main, yet still implicit, function of which was to mimic control. A corresponding question calls for attention: to what extent do modern biomedical practices ‘mimic’ control?

Implantation of a mechanical help-heart is (in emic terms) described as an evidence-based medical practice, the explicit function of which is (again in emic terms) to save people from dying. It is an institutionalized set of practices whose instrumental purpose is to exert control (medical cure/care, alleviation) over what is regarded as uncontrollable (disease, suffering, pain). As long as control can be exerted through these practices their explicit instrumental purpose is being met. But what about that which remains beyond control? Are there circumstances when ‘mimicking’ control can be ascribed to biomedical practices as their implicit instrumental purpose? This explicit focus on the instrumentality of the implantation of a mechanical help-heart seems to have escaped both the attention of Heartisans themselves and also of a scholar attention in general. Perhaps in contemporary anthropology such a strong emphasis on the instrumental purpose of ritual would on the whole come across as way too structural-functionalist and out of date. However, certain of its aspects may still be worth investigating, especially those revolving around what is beyond the reach of medical knowledge, i.e. its ‘unknowns’. In what ways is modern biomedicine dealing with uncertainty inherent to its practices? What counts as evidence in this evidence-based practice and according to what criteria? Or, in a word, which facts are, through biomedical practice, being selected as valid and meaningful evidence? Which are rejected? How is this selection linked to the participants’ understanding of factuality? And, finally,

what can we learn about Heartisan culture by paying attention to these implicit connotations to their routinized practices, to the fine-grained sensibilities that drive them, and to the patients' embodied senses of bodies, crisis, and hope?

Communication

Freud, drawing on the psychologically influenced anthropology of James George Frazer (1890; 1935[1910]), provocatively compared rituals to behaviors of obsessive neurotics. The main function of rituals, in Freud's perspective, is simply therapeutic. According to ritual theorist Catherine Bell, Freud viewed ritual as: "... an obsessive mechanism that attempts to appease repressed and tabooed desires by trying to solve the internal psychic conflicts that these desires cause" (1997). Freudian influence is also apparent in structural-functionalism of Evans-Pritchard and in Culture and Personality School of Ruth Benedict.

A quick glance in the rear-view mirror reveals a wide-ranging dissatisfaction amongst many scholars regarding these clearly instrumental and often completely non-cultural understandings of ritual. Turner, for instance, argued that: "... to equate [tribal] ritual with the obsessional 'rituals' of Western neurotics, as Freud did, is to rob it of its creative potentials" (1977: 40). The creativity of ritual is brought by the message conveyed in its very performance and also by the embodiment of this message through ritual performance. Nevertheless, while rituals communicate the cultural norms and values of their performers, their purpose goes beyond sheer maintenance of the societal structure. Through communication they are making and remaking this structure. This emphasis on the creative communicativeness of ritual is also present in Mary Douglas's critique of Durkheim's analysis. While agreeing with Durkheim that ritual is a social phenomenon, Douglas stressed that ritual in fact creates reality which could not exist without it: "... ritual does not play this secondary role. It can come first in formulating experience ... it modifies experience in so expressing it" (Ibid: 79). Finally, she sums

up her argument by pointing to creative powers of ritual: “The ritual is creative indeed. [It] creates harmonious worlds with ranked and ordered populations playing their appointed parts” (Ibid: 90). This creative power of ritual is also one of the cornerstones in my understanding of it. It rests more on the concept of ritual as primarily bodily practice. Hornborg (2005a) describes how bodies are, through formal ways of performance, being disciplined into a certain way of being in the world – an ongoing process which is pre-reflexive and therefore habitually taken for granted. This understanding fuses the Foucauldian concept of disciplined body with Bourdieuan concept of habitus in that it acknowledges the power of structural practices to carve their structures deep into the bodies that perform them. In similar fashion, Desjarlais (1992) emphasizes the importance of ritual as one of the rudimentary forms of the embodied aesthetics of everyday life: “The ways in which a given people build houses, conduct rituals, and tell stories influence the ways in which they experience their bodies” (Ibid: 39).

In general, the message communicated through certain ritual practices is made explicit while in others it is more conveyed and coded into symbols and aesthetics. Grimes argued that rituals “... inscribe images into the memories of participants, and they etch values into the cornerstones of social institutions” (2000: 5). There are three well-known anthropologists who are often depicted as the pioneers of symbolic and interpretative anthropology: Victor Turner, Clifford Geertz, and Mary Douglas. Their approaches are, however, quite different. Victor Turner, trained in British structural-functionalism, viewed symbols as the instruments for the continuation of society (1997[1969]). Clifford Geertz, on the other hand, adapting a stronger semiotic approach with focus on the analysis of meaning, explored culture in publically shared systems of symbols and actions (2000[1973]). Finally, Mary Douglas, with one foot in Lévi-Strauss’s structuralism and the other in Durkheimian collectivism, tried to identify and analyze the universal patterns of symbolism (2010[1966]). In spite of their diverse intellectual descent,

what these three scholars have in common is that they are concerned with interpretation of symbolic action, i.e. they study the practices by which people give meaning to their world and how this world is manifested in and through cultural symbols.

While all three theorists draw to a great extent on Lévi-Strauss's structuralism and his denial of evolutionist idea about intellectual differentiation between primitive (simple) and modern (sophisticated) thinking (Lévi-Strauss 1966) they are also critical of Lévi-Strauss's naturalization of culture. Turner, for instance, criticizes Lévi-Strauss for neglecting some of the essential parts of human life – emotions – and argues, with reference to his study of *Isoma* healing rituals among Ndembu in central Africa, that symbols and their relations are more than merely a set of cognitive classifications for ordering the Ndembu universe. He writes, “They are also, and perhaps more importantly, a set of evocative devices for rousing, channeling, and domesticating powerful emotions, such as hate, fear, affection, and grief [...] the whole person, not just the Ndembu ‘mind’, is existentially involved in the life or death issues with which *Isoma* is concerned” (1997[1969]: 42,43). This insight, as will be evident later, is of central importance to my analysis of clinical practices as an evocative device for eviction of fear and doubt on the one hand, and creation and maintenance of hope on the other. Geertz also makes similar remarks in his description of Lévi-Strauss's structuralism as “... an infernal culture machine [that] annuls history [and] reduces sentiment to a shadow of the intellect” (2000[1973]: 355). Finally, Douglas applies the structuralist classificatory systems to a society at large rather than to a cognitive function of individual highlighting its symbolical value, which is only effective when publically shared (2010[1966]).

The communicative creativity of ritual is addressed by Moore and Myerhoff in their definition of ritual as: “... a set of formal acts which deal with or refer to postulated matters about society or ideology (or matters those mounting the ritual *want* to be unquestioned)” (1977: 22). Furthermore, Rappaport acknowledged the power of ritual communication as it always, to a certain extent, expresses two

mutually constructive types of messages: one ('self-referential') transmitting information about the status and relations among individuals and groups performing the ritual and the other ('canonical') transmitting information about the order of things, i.e. "universal orders" (1999: 52-4). Here, the ritual communication is portrayed as a fundamental social act through which individuals make sense of themselves, each other, their relations, their place in the world, and ultimately also about the world itself. The canonical character of ritual, ascertained through its rigorous loyalty to established conventions, gives it a kind of authority that is above the will of the individual actor, i.e. a kind of a cultural guidance to be followed. Whatever its instrumental purpose, it speaks in the language of cultural norms and values, in dos and don'ts. Victor Turner also highlighted the creative power of ritual communication as it is manifested in the dialectic relation between the structure and anti-structure. Hence, the society is, according to Turner "... a process rather than a thing" continuously changing through the ritual (1997[1969]: 203).

Desjarlais (1992) takes us one step beyond merely semiotic interpretation of symbols, arguing that cultural forms⁶¹ should be regarded as deeply-felt aesthetic reflections of a culturally specific take on life, world, body, kin, community, health, and illness. To get to these aesthetic sensibilities of people's everyday life, Desjarlais holds, we need to go beyond merely telling a twitch from a blink: "... we must also consider why one blinks, the sensibilities that lend value to that act, and the effect that act might have on its participants" (Ibid: 248). The deeply-felt – or "felt sensibility" as Desjarlais calls it – that lies at the core of cultural forms, is the key to this understanding. Ultimately, such an understanding reveals the deeper and broader meaning of seemingly merely instrumental ritual practices (Ibid). Desjarlais seems to prefer not to distort the Yolmo (emic) explanation

⁶¹ Culturally specific styles of conducting rituals are, according to Desjarlais, one amongst several other such forms, such as styles of building houses, and of telling stories (pp 132).

of the instrumentality of their healing rituals (throwing out the demons to get rid of the harm) by forcing it into narrow frames of analytical (etic) categories and any alleged implicit instrumentality. Instead, he attempts to make sense of their culture through keen attention to the felt sensibilities which are manifest in their healing rituals – as if he were an archaeologist of emotions, brushing the semiotic soil off the local sensibilities, allowing for the cultural grid of the Yolmo world to come into view. This way, he learns the Yolmo people's tacit sense of moralities, body, healing, pain, and tacit moral codes such as values of presence, harmony and balance. These embodied sensibilities, in turn, "... influence how and why they fall ill, how they heal, and what moments of pain and comfort feel like" (Ibid: 248,49). Similarly, with regard to the earlier discussion of the explicit (emic) and implicit (etic) instrumentality of rituals (pp 125-127), by engaging in their healing rituals the Yolmo people are doing more than merely "throwing out the demons" – they are also being forced to rethink their understanding of their deepest sense of body, pain, right and wrong, healing, their relational selves, politics, society, and social history.

There is a kind of instrumentality, communicativeness, and creativity inherent in ritual that is essentially 'performative' in its ability to coordinate people to what might be called a total engagement: "The primary work of [rituals] is to ensure that we attend to such events fully, which is to say, spiritually, psychologically, and socially" (Grimes 2000: 5). This is particularly apparent in the case of mechanical help-heart implantation treatment, where both medical professionals and patients are ritually assembled in such a total engagement – doctors and nurses by being devoted to their calling; patients by being devoted to their doctors and nurses; and all of the above by being devoted to the power of medical knowledge, practice, and technology. Apart from the emphasis on 'performance' or 'action' as central to all rituals, this also implies that although psychologically and socially significant, ritual means something to us on yet another level – it is emotional. This brings ritual to yet another

level of engagement where it is even more meaningful. In the light of the theoretical discussion thus far it is safe to say that ritual plays an essential part in human lives on many different levels:

1. Social level – we use rituals to keep society going (Durkheim 1915)
2. Cultural level – we use rituals to extend the powers of our bodies in managing existence and creating and communicating meaning and to restructure our attitudes and relations in order to organize cultural phenomena (Benedict 1989[1934]; Douglas 2010[1966]; Evans-Pritchard 1976[1937]; Geertz 2000[1973]; Ortner 1973; Turner 1968)
3. Psychological /social level – we use rituals to manage our everyday social interaction (Goffman 2005[1967])
4. Psychological level – we use rituals as a ways to manage personal distress (Scheff, et al. 1977)
5. Emotional level – we use rituals to ensure ‘deeply into the bone’, wholehearted, total engagement reminiscent of spirituality (Grimes 2000)

However, as much as rituals are instrumental and communicative, they clearly also help in organizing cultural phenomena (Ortner 1973; 1978) and imposing a formal structure and sense of universal orders (Rappaport 1999), which brings us to the third quality of ritual – ordering (or formality).

Formality

Etymological origins of the term ‘ritual’, displayed in the beginning of this chapter, suggest that ritual is a way of creating structure out of chaos by repetitive practice (practice by numbers) and strict rules of conduct, making different elements fit together in a certain form, dramatizing the necessity of flow by simulating the strictly ordered course of actions, leveling things into a more even flow. In a case of mechanical help-heart implantation, then, it would be about rendering

the continuation of flow of life possible and reducing the impending threat of the unknown by routinized practice of taming through carefully organized conduct. On the whole, the repetitive and formalized quality of ritual practices renders them a most fertile way of generating and embodying meaning.

This etymological synthesis is reflected in several other descriptions of ritual. Catherine Bell shows this historical trace: “The earliest edition of Encyclopedia Britannica, put out between 1771 and 1852, defined ritual as a ‘book directing the order and manner to be observed in performing divine service in a particular church, diocese, or the like’” (Bell 1997: 259). Geertz described Balinese cockfight as an art form “... ordering [cultural themes] into an encompassing structure” (2000[1973]: 443, 444). Douglas talked about ritual as an ordering practice: “[It] creates harmonious worlds with ranked and ordered populations playing their appointed parts” (2010[1966]: 90).

To sum up, there is more to ritual than its instrumentality and aesthetics of performance alone reveal. Or in a word, besides being instrumental and communicative, they are also ordering. As we have already learned from the Desjarlais’ account on Tibetan Yolmo people (pp 134, 135), the ritual practices are rooted in local sensibilities, which is why the form of ritual conduct makes its participants rethink their understanding of their cultural norms and values. The etymological roots of the concept of ‘performance’ also reveal the ordering quality of ritual as it, according to Grimes (2008: 381), has at least two additional connotations in ordinary parlance: i) reflecting its etymological roots (Latin *per* = ‘through’ and *forma* = ‘form’) performance is an enactment of routinized, i.e. formal behavior⁶²; and ii) the term ‘performance’ also has the connotation of ‘achievement’ as it is conducted with the aim of bringing about change (Ibid.).

⁶² Grimes states that this connotation is called upon when we speak about ritual performances.

RITUAL – A WORKING DEFINITION

The three main features of rituals discussed so far resemble to some extent another attempt of categorizing main types of human behavior. Referring to the work of Edmund Leach, Victor Turner (1968) displayed three main types of human behavior which are not genetically determined:

1. Rational-technical behavior
2. Communicative behavior
3. Magical behavior

Turner concluded, in the words of Edmund Leach, that first and second categories ought to be brought together and included in the definition of 'ritual' which hitherto has been, by most anthropologists, reserved for the last category – magic. This position suits my aims here as I study clinical practices that are essentially believed to be: a) 'rational-technical' in that they rest on the concept of scientific rationality and are technology-bound; b) 'communicative' in that they are expressive and performed symbolical dramas echoing the ethos of Heartisan culture; and c) 'magical' in that they, at least metaphorically, hold the power to reveal the truth (i.e. the objective world of nature), to perform wonders (i.e. to 'assist' it), as well as the fact that they are always surrounded by aura of 'hope' (as in hope that they will actually work). This is why magic can also refer to less tangible ways of establishing the sense of trust and hope in times of doubt and despair. Therefore I adopt Leach's and Turner's suggestion that rituals to varying degrees are made up of these three qualities.

I do not wish to imply that clinical practices by any means are magical or that Heartisans themselves would ascribe such properties to them. My reason for including this concept in analysis is its persuasive occurrence in clinical rituals, as well as in discourses surrounding them, in a form of metaphor the symbolical value of which is closely related to the concepts of 'power', 'authority', 'trust', and 'hope', all of which are significant elements of these clinical rituals. People of Heartlands often use language of devotion when

speaking about their high-tech practices, dressing their utterances with concepts like ‘unbelievable’, ‘fantastic’, ‘miracles’, and ‘power’. What’s more, I believe that a more critical examination of these clinical rituals will shake the fundament of religious/secular division – one of my main theoretical points here. Thus, it will also dissolve the rigid concept of ‘magical’ as an exclusive property of “mystical powers” into a broader, more inclusive one, providing room for any kind of non-religious and non-mystical ‘power’ associated with these particular practices. Edmund Leach wrote, quoting Malinowski, that

[Every] ritual performance ... is a traditionally enacted miracle... Man needs miracles not because he is benighted through primitive stupidity, [or] through the trickery of a priesthood... but because he realizes at every stage of his development that the power of his body and of his mind are limited (1968: 523).

Moore and Myerhoff’s definition mentioned earlier (pp 133), also seems quite suitable for my purposes here as the particular rituals that I am studying can be claimed to be a “set of formal acts” that both “deal with” and “refer to postulated matters about [the ‘objective’ world of nature and the order of things]” (1977: 22). Moreover, the authors argue that this definition can be used for both religious and secular rituals – a circumstance that is especially apt for my aims of problematizing the religious/secular division⁶³.

Thus far, the synthesis of, on the one hand, the etymological traces displayed above and, on the other, several definitions which seem to echo the sentiment of these traces suggest that ritual is a distinct, formalized and, above all, cultural practice through which goals are achieved, sentiments are communicated and principal ethos is preserved by enacting meaning into the lived reality of people.

⁶³ Although the religious/non-religious and sacred/non-sacred division is a necessary first step in an attempt to separate the study of ritual from that of religion I would still like, as will be evident throughout this chapter, to push things one step further and in contrast to Moore and Myerhoff, eventually escape these divisions altogether.

Although the instrumental character of ritual can easily be discerned with reference to the emic answer to the question “why” a certain practice is performed, the communicative and ordering qualities of ritual seem rather hard to separate as they inflict on one another. As discussed earlier, the theories of embodying through practice suggest that any act of communication is at the same time an act of embodying the cultural norms and values as it is an act of expressing and thus also (re)creating them. This considered, I propose the following twofold working definition of ritual:

Ritual is a distinctive formalized practice through which goals are achieved, sentiments are expressed and principal norms and values are (re)created by enacting meaning into the lived reality of people with its essentially twofold feature as:

1. Rational-technical instrument – established and structured means of achieving a desired end (explicit operational significance).
2. Communicative-ordering practice – ritual is a dramatization of social life which, through symbolic performance, imposes an order, accounts for the origin and nature of that order and shapes people’s dispositions to experience that order (inherent interpretive significance).

This definition of ritual includes instrumental, communicative and ordering qualities and rests on the presumption that the shape and content of one quality is determined mutually by the other two. These qualities can easily be applied to biomedical healing rituals designed to deal with advanced heart failure. Their operational rationale is to extinguish or alleviate the burden of heart failure and to ultimately restore the heart’s pumping function, allowing the patient to go back to his or her life. Their communicative-ordering function, on the other hand, is to, through communicative enactment of its fundamental norms and values, legitimize, reinforce, sustain, and even

perfect: the existing tacit moral codes, cultural understanding of the body, illness and healing, and also established social order.

Ritualization

Numerous other qualities are often regarded as the property of rituals, the most exhaustive account of which is, perhaps, found in Grime's chart termed "Qualities of Ritual". The chart lists nearly 50 adjectives (for instance 'traditional', 'gestural', 'repetitive', 'collective', 'dramatic') and verb-like qualities (such as 'performed', 'embodied', 'enacted', 'standardized') typical of ritual as well as over 30 qualities that are not ritual (such as 'not ordinary', 'not personal', 'not unconscious') (1990: 14). Grimes preferred this chart to providing a single definition of ritual since as it would be less definitive and less obstructive while at the same time providing a thicker set of qualities for a ritual theorist to work with. Furthermore, he didn't claim that they all exist in all rituals or that any single one of them is unique to ritual. It is when these qualities "... begin to multiply, when an activity becomes dense with them, it becomes increasingly proper to speak of it as *ritualized*, if not a rite as such" (Ibid, my italics). Humphrey and Laidlaw are loud proponents of theoretical usage of this concept of *ritualization* – in a sense that rituals are but common acts performed in a ritualized way (Humphrey and Laidlaw 1994). According to them, these practices are sometimes attributed meaning by people performing them, and at other times not fully so. Yet, they are at all times stipulated beforehand as a part of a system of meaning. This is what makes them *ritualized*. The actors' intentionality is discounted in ritualized actions as they do not correspond to the kind of intentionality in everyday actions. Thus, they are committed to enact ritually what has been stipulated for them beforehand while their own direct intentionality is temporarily put aside. This means that "... in adopting a ritual stance [or attitude towards stipulated constitutive rules of ritualized action to be performed] one accepts ... that in a very important sense, one will not be the author of one's acts" (Ibid: 97). Rappaport refers to this as 'encoding', saying that in each ritual

there are messages which might be transmitted by the participants but are not encoded by them (1999: 52). He calls these messages ‘canonical’ and means that they stand for “... the general, enduring, or even eternal aspects of *universal orders* (Ibid: 53, italics in original).

Although I am, with regard to my empirical findings, not convinced about the accuracy of Humphrey and Laidlaw’s claim about complete absence of performer’s intentionality in ritualized actions, nor regarding the ‘eternal’ character of ‘universal orders’ proposed by Rappaport, I still think that the concept of *ritualization* provides a very useful perspective in ritual theory. Hence, it is primarily a slightly modified concept of *ritualization* – with moderate action-space available for an actor’s creativity (as opposed to complete absence of intentionality) and also suspended in a relatively durable web of shared beliefs (as opposed to ‘eternal universal order’) – that my analysis of clinical treatment of end-stage heart failure will rest on.

Rituals’ *instrumental*, *communicative* and *ordering* qualities seem to have attracted the attention of most scholars concerned with ritual theory. Perhaps this is the case because these qualities are rather broad and thus provide room for all, or at least most, other ritual qualities and are in no sense excluding. Therefore, they will be treated here as meta-qualities of ritualized clinical practices, allowing us to unveil the deep social, cultural and emotional dimensions of the implantation of mechanical help-hearts, and thereby also provide a more complex and nuanced picture of the potency and scope of these and other similar practices. As practices of implantation of mechanical help-hearts are essentially processual, transitional, and transformative a particular kind of ritual is interesting here, namely *rites of passage*. In following section I will provide a comprehensive outline of the theoretical framework of rites of passage, its origin, structure, and influence as well as its general structure.

rites of passage

Among anthropologists, the rituals that mark the transition from one condition to another – spatial (from one place to another), temporal (from one time period to another), group (from one group to another), and status (from one social status position to another) – are generally known as *rites of passage*. In the case of clinical practices it is a matter of transition from ‘the sick’ into ‘the cured’; from ‘pre-operation’ to ‘post-operation’; from ‘the defect’ into ‘the restored’; from ‘the disabled’ into ‘able-bodied’; from ‘the broken’ into ‘the repaired’.

Although it was Belgian anthropologist Arnold Van Gennep who was the first to elaborate on these particular rituals it wasn’t until more than half a century later, when British anthropologist Victor Turner⁶⁴ published his book *The Ritual Process: Structure and Anti-structure*, that rites of passage became a widely spread and quite popular concept (Turner 1997[1969]; van Gennep 1960[1908]). ‘Rites of passage’ is an umbrella term that assembles a range of formalized ways of dealing with crisis caused by various transitions in our lives. They can include the change from boy to a man, to a warrior, or to a chief; from girl to a woman, or to a wife; from ill and weak to healed and strong (1960[1908]). Some examples of these rites, as explained by van Gennep, include birthdays, weddings, funerals, graduations, and initiations. Rites of passage are further subdivided into:

1. Rites of separation (preliminal rites)
2. Transition rites (liminal rites)
3. Rites of incorporation (postliminal rites)

“Liminality” is a concept derived from the Latin *limen* meaning “threshold” (Encyclopaedia-Britannica 2010a) and is used by van Gennep to denote the marginal – in-between – character of transition. In the rites of separation an individual is removed from the social structure. Through the order and rules of conduct of ritual, the individual is being decontextualized. Transition rites (liminal rites)

⁶⁴ For more detailed account of Turner’s work see pp 145-149.

mark the phase where the actual transformation is taking place. During this phase an individual's status is ambiguous as he or she passes through the cultural bubble with no signs of the state of things either as they were or as they will be. Their behavior is submissive and they are expected to obey the orders compliantly and absolutely. The transformation is completed through the rites of incorporation where

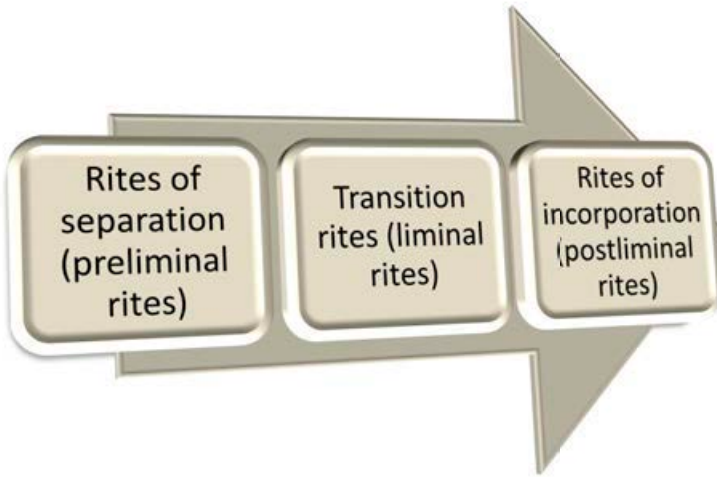


Figure 17: Tripartite processual structure of rites of passage with transitional stage of “liminality” in the middle.

the individual is reintegrated into society – only this time with the new status. The purpose of a rite of passage is to alter the individual socially and culturally in order to optimize him or her for the new life. Thus, they come out of the rite with higher status, increased level of consciousness or knowledge, or with an upgraded social position. This model of *rites of passage*, borrowed from Turner's and van Gennep's study of ritual, is especially suitable for the characterization of the mechanical help-heart treatment as a healing ritual. First, the tripartite processual structure of rites of passage is fully identical with that of clinical treatment of end-stage heart failure:

1. A person with a sick heart is separated from the context of his or her daily life through rites of separation (diagnosis and hospitalization)
2. This is followed by practices enabling transition from ill to well (mechanical help-heart treatment)
3. Finally, a person is incorporated back into his or her daily life (discharge from the hospital).

During the first stage, a person is decontextualized and ascribed patienthood away from the familiarity of their homes, friends, and relatives. During the second stage, the sick person is in the midst of a transition which is characterized by the ambiguity of being neither here nor there – neither sick nor cured. The third, and final stage, is when the person after the successful treatment returns to his or her daily life at home. In order to understand the rites of passage in greater detail, a more comprehensive description of its central concepts of ‘liminality’ and ‘communitas’ is needed.

Liminality

One specific feature of rites of passage in particular was made by both van Gennep and Turner into their very hallmarks – liminality. According to van Gennep the general idea is that people’s lives are made up of a succession of changes, i.e. a series of passages, which in their very essence are disturbing for the life of society and the individual (hence the attribute ‘life crisis’) and “... it is the function of rites of passage to reduce their harmful effects” (1960[1908]: 13). Van Gennep also recognized that the rites of passage may further be subdivided into: a) rites of separation – *preliminal rites*; b) rites of transition – *liminal rites*; and c) rites of incorporation – *postliminal rites*.

While van Gennep held that this pattern was an ideal type of a complete scheme of rites of passage and that, in reality, these three types are not always equally important or equally elaborate, Victor Turner acknowledged the tripartite structure of such rites and put most emphasis on the middle phase, the liminal phase, where actual

transition takes place. Derived from the Latin *limen* meaning “threshold”, liminality is seen by Turner as the state “betwixt-and-between” the established states. It is marked by ambiguity and an elusive sense of identity and of being in the world – neither here nor there, but in between. Turner is not as interested in all transitions as van Gennep and focuses instead on *healing rituals* in particular, as they are performed among the Ndembu in central Africa.

The phase of separation – or the preliminal state – is where the neophytes (patients, liminaries) are detached from their mundane structural context. Their seclusion is dramatized through ritual performance of their ‘invisibility’ and is often marked by removal of any insignia that emphasizes their previous selves, such as names or clothes. In addition, they are required to behave and speak in certain strictly prescribed ways and to learn the special liminal vocabulary. Through the ritual, the neophytes are reduced to a lowest common social denominator, what Turner refers to as “homogeneous social matter” so that they can be remade into a new, better, form (Turner 1977: 37). So the rite of passage is in its essence transformative – the neophyte is expected to exit the ritual changed and optimized to better meet the new conditions. Thus, the rite of passage carries a person from one social identity to another⁶⁵. The ‘grinding down’ is accomplished through the process of deconstruction where all the things that belong to the world as one know it are peeled off, layer by layer, until the reverse anti-structure context is reached⁶⁶. Simultaneously with this process of grinding down, neophytes are being put through another parallel process – reconstruction. Reconstruction is accomplished through such processes as sacred,

⁶⁵ A young boy becomes a man, a man becomes a warrior or a chief, a young girl becomes a woman, single become wedded, living become dead, etc.

⁶⁶ During the ‘grinding down’ the neophytes are exposed to various trials: circumcision, clitoridectomy, subincision, hazing, exposure to extreme heat and extreme cold, unfeasible physical tests and riddles-with-no-answer where a novice’s failure to provide the answer is met by ridicule and mockery and further physical punishment, the aim of which is to enhance the regression of the neophytes – until they are ground down properly.

spiritual as well as practical, instructions, revelations of sacred objects, and recited myths. The contradictory coexistence of deconstruction and reconstruction mirrors the ambiguous character of liminality; it is but the upside-down world of paradox in which the reality of the lived world (actuality) is replaced by a make-believe world (possibility) in order to coerce the neophyte to pay attention and recognize as valuable all the things that are taken for granted as part of everyday monotony (Turner 1977: 38). The pervading symbolism in the liminal phase surfaces through metaphoric expressions with particular emphasis on death ('grinding down') and birth ('reconstruction'). This becomes clear in a prayer recited by the Ndembu ritual leader before the congregation as a part of the chief-installation rite: "Listen all you people. Kanongesha has come to be born into the chieftainship today" (Turner 1997[1969]: 105). This symbolical *upgrading* is done through the dramatic ambiguity of the liminal stage which Turner describes as a "betwixt-and-between" world of harsh make-believe where anything is possible – the anti-structure. Finally, yet another concept that Turner uses in his study of rites of passage to describe the sense of community that develops among the liminaries – *communitas* – will be used here.

Communitas

A ritualized sense of community, which Durkheim named "collective effervescence" (1915) was called "communitas" by Turner (1997[1969]). Both concepts regard the sense of community as a collective experience that surfaces and is boosted through ritual performance. The difference is that, while for Durkheim it is about the inherent mechanism of society's reproduction of itself, for Turner it is about confirmation of communal unity in contrast to the tensions, limitations, and competitiveness of everyday life. The individuals undergoing the ritual experience the sense of sharing on a different, existential level. It is about an "essential and generic human bond" that is always lurking behind the curtain of commonness of everyday life: the danger of poverty, social abandonment, oppression,

violence, marginalization, banning, illness, death or any other kind of misfortune. It is the mishap that brings people together in their shared experience of suffering, pain, abandonment, refuge, or exile, etc. *Communitas*⁶⁷ take place in a structural void from which social structure belongs to the realms of the past and of the future (Turner 1997[1969]: 113).

In this thesis, when I speak of liminality, I address two things, namely patients' existential state of dwelling: i) in between two social structures (between societal life before and after hospitalization); and also ii) in between two modes of existence (sick/healthy, dying/recovering, dependent/autonomous etc). On the other hand, when I use the concept of *communitas* it will be to describe ritual ways of upholding the sense of belonging to a Heartisan community.

⁶⁷ Turner points out several examples of *communitas* that have emerged in modern Western society such as beatniks and hippies. If he had written his book during the World War I he would probably have written about Dadaism. If, on the other hand, he had written his book a decade later, he'd probably also name Rude Boys and Rude Girls of the British wave of Ska movement, the Mods, and the Punks. Since the early eighties there are the Glam Rockers, Metal-heads, the EMO kids (emotional hardcore), the Straight Edge movement, Cultural Jammers, the Green Peace movement, Attac, etc. All of these are collective expressions caused by a shared sense of marginalization, political oppression, industrial and capitalist exploitation, and economic globalisation. In this day and age we have countless refugees forming diasporas around the world as one of the most brutal examples of the postmodern type of *communitas*. Another tragic example would be populations caught in a war zone – such as the women of Sarajevo living for years under the siege during the war in Bosnia (see, for instance, Carol Mann 2006, *Kucne amazonke : otpor zena iz Dobrinje, predgrada Sarajeva*. Translated by M. Stevanovic, published by "Svjetlost", Sarajevo). In addition, immigrants, poor, alcoholics, drug abusers and other rejects of society are secluded and bracketed from the dominant stream of social life almost everywhere. These circumstances create the sense of not belonging to society – while belonging to the *communitas* of rejects – which in turn renders integration troublesome or even utopian. On the global level there are forces forming economical and political unions isolating the poor countries and regions from the benefits of growth and prosperity.

RITUAL THEORY – CRISIS AND NEW APPROACH

Ritual has often been described as essentially a religious practice and was, as such, given a central role in the theoretical depiction and interpretation of religion (Bell 1987; Bell 1992). The Durkheimian claim that rituals belong to the domain of the ‘sacred’, which he equates with that of ‘religion’ (1915), made a deep impression in the development of ritual theory in general where this dichotomy between ‘belief’ and ‘ritual’ is tied to a broader theoretical conceptual dichotomy between ‘thought’ and ‘action’ as a primary grid of any ritual (Bell 1992). At the same time, the modern high-tech clinical practices are regarded both by Heartisans and by society in general as ‘scientific’ and ‘evidence-based’, hence inherently rejecting any connection to religion. And yet, both of these ascribed attributes clearly command *respect*, assure *validity* and impose *authority*, all of which are qualities which also are commonly found within the realm of religion. This is not to say that these practices are religious but simply that they, while being deeply rooted in medical science and secular worldview, are also suspended in specific a cultural web of meaning and shared beliefs.

In this section I will argue that this still very influential yet clearly old-fashioned Durkheimian position should be reassessed in the light of contemporary context, both on local and global levels. Moreover, I will also argue that the religious/secular (sacred/non-sacred) dichotomy should be abandoned. However, I don’t think religion, should it prove to be a significant part of a particular ritual, must be ignored as such. My suggestion is that religion should be denied its *a priori* status as a key element of understanding *any* given ritual. Still, renouncing the dominance of the concept of *religion* in ritual theory does not imply renouncing the *belief* from ritual practice. Although I do think that Moore and Myerhoff’s distinction between religious and secular rituals might seem practical, as it allows even for many non-religious formalized practices to qualify as rituals, I still find it limiting as it also erases ‘belief’ as an integral part of these rituals. Furthermore, I am convinced that it is possible, even desirable, to

reject the flat old-fashioned *thought/action* dichotomy without rejecting the belief as an integral part of ritual practice. Hence, I am critical of Grimes's position that it is a mistake to speak of belief as a source of ritual practice (1990: 9). Similar to Grimes, Hornborg also emphasizes that people can take part in rituals without actually believing (2005b: 15). Reasonable as this statement is, however, if we should take 'believing' to mean anything else than knowingly giving a meaning to acts performed, it falls flat. Ultimately, discarding the participants' believing altogether risks reducing ritual practice to, as Staal would have it, completely meaningless activity (1979). In her later work, however, Hornborg analyzed the increasingly popular modern ritualized practices in a secular Swedish society – practices aiming at improved individual well-being⁶⁸ and general good health. These ritualized practices have proved to be a rather lucrative business idea – commodities that can be bought and sold – attracting more and more Swedes to invest their time and money. Good health is thus portrayed as the ultimate aspiration of mankind, which is why we, according to Hornborg, can speak of the birth of a new religion, the "Religion of health" (Ibid: 153). Obviously, there are at least some aspects of these ritualized practices that rest on some shared beliefs: even if we don't really believe that a specific mud spa treatment will make our skin breathe and glow so as to actually make us look ten years younger, we still seem willing to spend our time and money on these treatments, *believing* the maxim that "it's good for you!".

Before deciding beforehand whether rituals are to be described as religious or secular or whether their performance is linked to some kind of belief or not, perhaps we should ask ourselves whether ritualized practices that are regarded as completely devoid of belief are also detached from any ontological fundament, i.e. culturally unsituated? Is this even possible? It seems as if not only our understanding of ritual but also that of belief has been infected by stubborn theoretical focus on religion for over a century. Everything

⁶⁸ Rapidly increasing spa facilities, including 'health farms', health resorts, health restaurants, workout gymnasiums, well-being courses, and coaching.

takes place as if both the concepts of belief and ritual, instead of being rejected, need to be freed from the iron grip of the concept of religion.

Performativity in focus

Religiousness of ritual (and of belief) is the key aspect of Durkheim's ritual theory. Nevertheless, it has also been the subject of heated intellectual debate during the last third of the past century (Moore and Myerhoff 1977). While many scholars continued struggling with the perplexing weight of religious/secular dichotomy in the study of rituals, others have lately chosen to partially or completely turn away from the concept of ritual itself, turning instead towards wider and perhaps more tolerant concepts of 'performance'⁶⁹ (Grimes 2008; Schechner 1988; Turner 1986), 'social drama', 'theatrical paradigm' (Goffman 1961; Goffman 2005[1967]; Schechner 1988; Turner 1986), and 'praxis' (Bell 1997; Bourdieu 1977). Still, many times, these 'new' concepts seem to be deployed only as euphemisms for troublesome concept of ritual, allowing the scientists to escape the trap of religiousness or sacredness of ritual. Instead they could focus on social aspects of 'plot' being put on public display through 'performance'. Although obviously pragmatic and important, this approach seems to have one major shortcoming – it fails to recognize the inherent rituality in these various genres of performance and practices.

At the end of the last century, the theoretical debate on ritual seems to have become rather stagnant. At the same time, 'performativity' and 'performance' have become new buzzwords attracting more and more scholars from cultural and feminist studies, anthropology and philosophy where these 'performative' features of human practice have gained a whole new life⁷⁰. It seems as if the debate on *religiousness* in ritual has become a rather heavy load – an

⁶⁹ Ritual being but one amongst other genres of performance such as theatre plays or social games.

⁷⁰ The majority of these studies have nothing to do with ritual whatsoever.

insurmountable obstacle – not as much for Ritual Studies as for the ritual theory in a broad sense. We seem to need a new approach where ritual is carefully disentangled from the knotty definitions (which are built-upon the structure of conceptual dualisms that are far too including for some practices and far too excluding for other). In a sense it can be argued that ritual is, just like the transition stage of rite of passage, liminal at the very core of its existence, it escapes the narrow frames of conceptual boundaries and definitions; neither religious nor secular, but both at once. Therefore, if we wish to study and understand rituals we can no longer afford the blindfold of the religious/secular dichotomy.

Religious vs. secular

The old *sacred/profane* dichotomy proposed by Durkheim has two major conceptual implications: first, it treats the *sacred* and *religious* as if they were one and the same, and second, its opposites, *profane* and *mundane* are treated the same way. Durkheim tried to avoid this conceptual trap of simplification by assuring that anything, not only gods, can be sacred: a rock, a tree, a spring, a piece of wood (1915: 36). This assertion, whether it mirrors ethnographically observed animism or an ethnocentric attempt to project this understanding onto the big picture of all mankind, looks more like an *ad hoc* safeguarding than a very strong argument. Moore and Myerhoff were critical of this postulate: “All of life can be sacralized in this way...” (1977: 23). Instead, they argued, any dichotomy between sacred and profane is first and foremost a conceptual categorization, the original content and form of which is always culture-bound rather than universal. Although Durkheim, by asserting that what counts as sacred “varies infinitely, according to different religions” (1915: 36), did recognize the culture as the key determinant of what is seen as sacred by a particular religion in a particular society, he never distinguished between these two concepts. He assumed instead that the sacred is a material reification of religious beliefs – concrete objects of worship. This is exactly what Moore and Myerhoff oppose

by asserting that while some sacred things are also religious, there are certain things in all societies that might be regarded as sacred without reference to any religion. Indeed, if understood literally, Durkheim's classification of the world into sacred and profane rules out all non-religious rituals as non-sacred and thus also as not qualifying as rituals at all. Instead of the sacred/profane dichotomy Moore and Myerhoff propose a more multifaceted fourfold set of categories⁷¹ which they deem as "capable of generating more combinations than Durkheim's sacred/profane and [thus] susceptible of less confusion". They tell us that ritual practices can be 'secular', i.e. detached from the structure of any overriding religion. Nevertheless, this does not imply that rituals should be denied any sacredness or spiritual dimension. The answer to the question of "what do different peoples regard as sacred?" is fundamentally manifold. 'Sacred' might, on the one hand, be something valued, appreciated, treasured, cherished, beloved, *or* on the other hand, something revered, feared, worshiped, or adored – or anything in between. The same goes for the question of what people mean when they devote themselves to something spiritually. It may mean morally, emotionally, ideologically and wholeheartedly *or* it may also mean piously, religiously – or anything in-between. Any definition of sacredness and/or spirituality is fundamentally culture-bound – even situational – and by no means universal.

Rappaport also acknowledges the concept of religion as 'irreducibly vague' although he remains loyal to its relevance for defining and theorizing ritual. He equates religion with the concept of 'holy', which he then dismantles into several smaller constituents: sacred, numinous, occult, and divine. By discerning and defining these nuances of 'holy' Rappaport points out the complexity of religion while at the same time arguing that it is through the ritual that the

⁷¹ **Religious/sacred** (such as the last rites, baptism, Sunday services, the Corpus Christi procession, Muslim Hajj); **religious/non-sacred** (the courtroom oath with the hand on the Bible, Christmas); **non-religious/sacred** (the Hippocratic Oath, pledge of allegiance to the national flag); and **non-religious/non-sacred** (civil rituals such as birthday parties, engagement parties, romantic dinners, Thanksgiving, graduation ceremonies, and International Worker's Day).

integration of the four ‘constituents’ into the ‘holy’ is achieved. In his attempt to grasp the term ‘ritual’, on the other hand, Rappaport argues that we should be seeking for the universals among the religious and other rituals as that can help us “distinguish them from each other more clearly later, and distinguishing religious from other ritual will be helpful in fashioning conceptions of the sacred, the numinous, and the holy” (1999: 25). This appears to be a strategy quite close to that of Moore and Myerhoff. Nevertheless, both strategies are still clearly ensnared in the religious/non-religious dichotomy as one of the crucial conceptual distinction in ritual theory. In the following I will critically review this emphasis on religion/non-religion among the ritual theorists, with a particular focus on magic (as a property of religion and religious rituals) and science (as representative of secular rationality). Drawing from my own use of ritual theory as an analytical tool in approaching my data, I will argue that the status of this old-fashioned dichotomy as an inherent element of theoretical defining of ritual should be reconsidered and redefined.

Due to the essentially cultural quality of the meaning of sacredness and spirituality, the efforts to distinguish between religious and secular rituals have been made the target of numerous discussions and have often proven to be quite a slippery subject to handle. For instance, many scholars have emphasized the interesting ways in which religious beliefs, myths, and rituals in fact resemble what we know as logical or scientific knowledge (Durkheim 1915: 203; Evans-Pritchard 1976[1937]: 222; Lévi-Strauss 1966). Stanley Tambiah pushes this thought one step further by reminding us that science as we know it today is in fact deeply rooted in religion. He points out that while Greek philosophers and forerunners of science did distinguish “... between magic and medicine (‘science’), they did not oppose ‘religion’ to them as a third category” (Tambiah 1990: 11). In a sense, then, religion seems to have functioned as a common denominator of these practices, a view clearly stated in the following ‘formula’ offered by Tambiah (Ibid):

magic/medicine ("science")/philosophy
religion (pervasive divinity)

On the other hand, as far back as the early 1920s, Malinowski argued that magic used among the Trobriand Islanders is considered to be a specific power that is “essentially human”. This magic, as Malinowski looked at it, is made of words and actions that were not mediated by any other agency such as gods, or spirits (2002[1922]: 427). Instead, Malinowski explains, it is in fact the sheer belief in the power of words and rites that was the “... basic dogma of [Trobriand Islanders] creed” (Ibid: 427). Spells and ritual actions are believed to be constituted in and through the collective heritage, which is why they never can change but must remain the same and true to the ancestral legacy if they are to retain their power (Ibid: 427). Perhaps the most interesting thing here is that, although Malinowski doesn’t make any explicit connection of Trobriand magic to any kind of Trobriand religion, he still recognizes mystical elements and powers that are ascribed to these words and acts.

A similar sentiment is expressed in Durkheim’s study of Australian aborigines, discussed earlier. When asked about the purpose of their rituals the natives are not primarily referring to their gods but say instead that their rituals come from the ancestors. Furthermore, they unequivocally acknowledge that they perform rituals to remain faithful to the past (1915: 371). In spite of the natives’ reference to their ancestry Durkheim explicitly ascribes religiousness to their rituals, in contrast to Malinowski, who just lets it remain implicitly assumed. According to both examples, however, it seems as if it was tradition that is treated as if it were a religion. The question follows: are mystical elements (read unexplainable or transcending the scope of human understanding) of Trobriand and Australian aborigines’ magical spells and rites enough to interpret their belief in and reverence before their tradition as religion? It seems to have been for Malinowski and Durkheim. How can we, in the light of this example, think about the things we do in our contemporary

technologized world? Suppose Trobriand Islanders' belief in tradition is not religion? That would imply that belief is not an exclusive property of religion. Instead, religion is but one of many possible manifestations of belief. Similarly, we can say that our belief in progress through scientific and technological development is not a religion – but it is belief nonetheless. Although secular, it is culturally revered as essential and is, as empirical examples will demonstrate, often enacted with deference and spoken of in a language of devotion. On the other hand, if we assume that their tradition *is* also their religion, could we also think of our belief in progress and technology as religion? Malinowski's Trobriand Islanders worshiped and celebrated their past by the means of magic spells and actions. Could it, then, be said that our modern highly technologized and strictly scientific clinicians worship and celebrate the future by ritual performance of experimental medical science and clinical medicine? Ultimately, it is a historical fact that the emergence of 'secular' is a result of scientific expurgation of 'religion' – not of belief.

Although I do recognize that a more detailed discussion, and perhaps even an attempt to define the concepts of 'religion' and 'belief', could be of great importance for my purposes here, I will refrain from doing so as it is too large a task to fit within the scope of this study. On the other hand, I will address the implicit and explicit denunciation of any kind of affiliation to 'religion' among the Heartisans who always readily present themselves as 'secular' *par excellence*. This attitude becomes particularly apparent in the ways Heartisans speak of their knowledge as certain and true. As the ethnographic evidence throughout these theses will demonstrate, Heartisan understanding is not considered a matter of belief, but of 'knowledge'. It is about the way things 'are'; it is not religious but rather secular as it is based on experience and scientific evidence (hence the concept of "evidence-based" medical practice). Heartisans give an impression of their practice as being governed solely by a coherent structure of well-established facts with no place for 'mystical elements' such as those found among tribal societies. In the

meanwhile, their practice is always and at all times threatened by various uncertainties and unexplainables. This study shows that this indeterminacy, inherent in modern biomedical practice and regarded as its most undesired element, is managed with rigorous routinizations and formalization of practice – *ritualization*.

If the concept of ‘religious’ or ‘sacred’ is excluded as a requirement for a set of formalized practices to qualify as ‘ritual’, the critics might point at the risk of exaggerated applicability of the label ‘ritual’ onto all formalistic types of behavior, turning the concept into absurd intellectual redundancy (Moore and Myerhoff 1977). Max Gluckman has tried to solve this problem by simply distinguishing the ‘ritual’ from ‘ceremonial’. While he regarded both ritual and ceremony as highly conventionalized performances, Gluckman asserted that the ‘ritual’ is based on utilization of mystical elements while the ‘ceremony’ has no such elements at all (2006[1965]: 251). Malinowski made a distinction between these two terms almost half a century earlier, but according to him magical and mystical elements were natural parts of all such practices: “In calling a magical action ‘ceremonial’ we imply that it was done with a big public attendance; under the observance of definite rules of behavior by spectators as well as by the performer. [Thus] magical rites may or may not be ceremonial ...” (Malinowski 2002[1922]: 425).

In spite of the efforts of a handful of scholars to delineate and separate the terms ‘rite’, ‘ritual’, and ‘ceremony’ they remained, for the most part, in each other's pockets and are to this day used indiscriminately almost as if they were synonyms. Moore and Myerhoff portrayed this situation quite clearly in their introduction to the *Secular Ritual*⁷² anthology: “It is clear that the articles in this volume do not reflect consensus on these matters and their usage remains inconsistent. Most often the terms, *ritual* and *ceremony*, were used interchangeably despite the general awareness of the confusion

⁷² This book is the end result of a conference held in 1974 that brought together a number of distinguished ritual theorists under the topic “Secular Rituals Considered: Prolegomena Toward a Theory of Ritual, Ceremony and Formality”.

surrounding them” (1977: 21, italics in original). I see no point in separating the terms according to the degree of presence of ‘mystical elements’ as Gluckman would have had it, neither do I see why a ceremony could not be performed before a ‘small’ audience, or in front of the mystical forces and powers, to challenge Malinowski’s demarcation. Hence, my aim here is not to distinguish these terms from one another. In order not to complicate matters in this thesis my usage of these terms will be just as interchangeable as it seems to be in the dominant theoretical discourse.

Ritual and rationality

It seems as if our fixation on religion, in the context of ritual, is at least to a certain extent rooted in the old-fashioned take on ritual as an irrational activity (as opposed to a rational secular/scientific one). Let us, for a moment, get back to the concept of mystical action addressed by Gluckman above. Jack Goody refers to ‘magical action’ as consisting of such mystical elements and makes a clearly ethnocentric claim that this magical action is “... essentially irrational, since it has a pragmatic end which its procedures fail to achieve” (1961: 159). A couple of years later Evans-Pritchard showed, in his renowned study *Witchcraft, Oracles, and Magic Among the Azande*, that, as the magical action “... transcends experience, it cannot easily be contradicted by experience” (1976[1937]: 201). He also points out that the *witchcraft/oracles/magic* triad forms an intellectually coherent system for the Azande and cannot as such be considered as irrational. Philosopher Martin Hollis approved of Evans-Pritchard’s approach, principally for regarding the Azande’s way of thinking and behaving about their rituals as “... rational by our [Western, scientific] standards of rationality ...” (1968: 236). Hollis argues that this is the only way to even begin to identify a system of belief that is connected to the ritual. Although the effectiveness of ritual might be recognized as empirically false by a researcher it should still be *a priori* assumed to rest on the same standards of rationality as those of the researcher him- or herself (Ibid: 243). Thus far, ethnocentric takes on both

concepts of belief and of rationality have been dominant within ritual theory, failing to recognize them as culturally diverse.

Nearly two decades after proclaiming magical action as irrational, Goody, without mentioning either Evans-Pritchard's important work or the subject of irrationality of magical action which he discussed earlier, suggested that the concept of 'ritual' should be discarded as it has proved to be analytically useless and generally confusing (1977: 25). Goody recognized the problem as essentially definitional, but was at the same time skeptical about whether it was at all worth the effort invested to solve it. Furthermore, Goody cited Turner's definition: "By 'ritual' I mean prescribed formal behavior for occasions not given over to technological routine, having reference to beliefs in mystical beings or powers" (Goody 1977: 27; Turner 1973[1967]). Although Goody found this definition to be insignificant, he also stated that it can be altered in order to provide room for secular rituals. All that needs to be done is to ignore the "reference to beliefs and mystical beings or powers" part. He also found the reference to "technological" to be somewhat problematic as it is but a differentiating factor, the meaning of which is derived from the relationship between *means* and *end*, a relationship which in turn is always culture-bound. It is quite easy to see how such scrutiny holds the power to dissolve the outlines and blur the boundaries of most definitions. Hence, it also reveals the unstable and fragile character of such definitive definitions and opens up for the possibility of further critical examination. It will, throughout this thesis, be apparent that my own view of 'ritual' clashes with this particular definition suggested by Turner. My study revolves around clinical "routines" that are essentially "technological" and are explicitly regarded by Heartisans themselves as fundamentally devoid of "beliefs in mystical beings or powers". Turner was studying the healing rituals in a tribal society. I am studying the progressive curing rituals of scientifically technologized society. Strathern and Stewart tell us that "... biotechnology has come to take place of rituals, spells, and prayers [and] has now simply made possible processes that people have

desired and magically simulated or earnestly prayed for in the past, and still do, in all parts of the world” (1999: 167). These local deployments of biotechnology must be put in the context where they operate. Indeed, throughout this thesis I will demonstrate with help of ethnographic evidence that what ‘technology’ is to late modern Western society (largely referred to as ‘secular’ with specific emphasis on scientific, technological and economical growth) corresponds on many levels with what ‘magic’ is to ‘religious’ tribal societies.

Ritual theory – new approach

The ‘essentially definitional’ problem of ritual stated by Goody seems to have been at the core of ritual studies for as long as they have existed but has grown beyond recognition as ritual (far too often regarded as property of religion) was documented as phenomenon in secular world (usually regarded as free from religion, belief, the ‘sacred’, magic and mystical powers). This seems to have caused a number of scholars to abandon the concept of ritual altogether⁷³. Nevertheless, while turning away from ‘ritual’ towards concepts of ‘performance’ and ‘social drama’ is obviously a pragmatically sound move, it also seriously undermines the ‘ritual’ as but one amongst many possible qualities of such kinds of practices. I am still convinced that there are significant benefits, both theoretical and analytical, in holding on to ritual as a primary, or a dispositional umbrella-concept of a group of formalized communicative practices which also are performed and dramatized. After all, a performance can be informal (instead of formal), improvised or spontaneous (instead of ordered), disoriented (instead of instrumental) and explorative (instead of expressive). As such, it can only be regarded as a non-ritual *par excellence*. A ritual, on the other hand, can never in its entirety exist outside of its performance.

This old-fashioned dominance of *religious/secular* dichotomy in ritual theory as one of the key conceptual determinants, or differentiating factors, is obviously too complicated and problematic

⁷³ As was proposed by Goody earlier (pp 158).

for analytical and theoretical purposes of any study of ritual practices, especially those surrounding science and technology. Each term – ‘religious’ *and* ‘secular’ – is a carrier of a multiplicity of value-laden connotations, many of which are often either irrelevant to the subject under discussion or downright misleading – or both. Therefore, it brings more distortion than clarity to any attempt to understand these practices. On the one hand, the concept of ‘religion’ is strongly linked to worship of divinity and carries heavy connotations of a shrine and clergy. It represents heartfelt beliefs as opposed to rationally inferred, evidence-based scientific knowledge about the world. On the other hand, the concept of ‘secular’ is linked to ideas of rational thinking and scientifically confirmed knowledge denouncing all kind of ‘sacredness’ together with the exclusion of belief and religion, resulting in a quite flat picture of the world. Thus, religious/secular distinction should be abandoned as a dominant conceptual determinant of ritual. Instead, ‘religion’ may or may not be a characteristic of a given ritual. Hence, whether a given ritual is religious or not is useless as a criterion for determining whether certain practices are rituals or not – it is an empirical question (of secondary order) which can help us penetrate deeper into the nature of ritual at hand instead of determining the sheer existence of ritual. Or in a word, whether a certain set of practices is to be called ritual or not has nothing to do with whether they are religious or not. What seems universal throughout the spectra of different ritual practices (again, religious or not) is the dynamic bond between:

1. What is at stake – for instance illness to be cured, life to be saved, predicament to be circumvented.
2. What are the social/structural conditions – the social structure of the field wherein ritual takes place, the status position, the roles and relationships amongst the actors and forces involved.
3. What are the dominant cultural underpinnings (ontological fundament) – the generally shared understanding about the

‘order of things’, tacit moral codes, norms and values connected to body, illness, health, life, death, pain, and hope.

‘At stake’ stands for concrete minutiae of phenomena including understanding of the nature and scope of the particular difficulty that needs to be managed and the strategies (practices, techniques) developed for that purpose. The social/structural conditions are observably manifested through performance of these strategies and can be said to represent what Rappaport has called the ‘self-referential’ message in ritual. The ontological fundament stands for its ‘canonical’ equivalent (1999). I consider these two levels of communicativeness of ritual – ‘self-referential’ and ‘canonical’ – to be particularly useful as they allow us to link concrete problems to the context of their social structure. They also allow us to link these same problems further to their ontological fundamentals (or a system of shared understanding) without any a priori built-in reference to religion, mystical powers, and magic. Thus, I adopt this approach as it can house both religious and non-religious rituals.

Before we get acquainted with daily life in Heartlands I will return to my outline of a working definition of the concept of ‘ritual’, explain briefly how it was built, and ultimately make clear how it will be used to suite the purpose of this study.

SUMMARY

Ritual and the clinic

I am concerned with particular kinds of practices – biomedical clinical practices. I look at these biomedical clinical practices as rituals, which means that I have chosen the concept of ritual as an analytical key to revealing and making sense of various cultural patterns and connections of everyday life in Heartlands. What is it that makes biomedical clinical practices ritual? Clinical practices are organized ways of acting in given circumstances. The structure of this organization rests on certain norms and values representative of the Heartlands culture. Therefore, these practices give expression to and

create the existing norms and values in Heartlands. Heartisans do things, i.e. they perform their professional roles. They don't perform as private persons, expressing their private personal desires or pursuing their personal goals (although this doesn't mean that their personal desires and goals don't cohere with their professional ones). Their work is cast in strictly organized templates, conventions, rules, guidelines and regulations based on shared understanding of how clinical work should be performed. Hence, it is safe to say that biomedical clinical practices in Heartlands are organized in accordance with collectively shared beliefs about: a) how things should be done; b) what assumptions and understandings these practices should rest on; and c) how these practices can be evaluated. Thus, these practices are always, to a great extent, organized independently of individual participants – or, at least, their structure is not under the direct control of the individuals. This is termed by Rappaport 'the first feature of ritual': "... the performers of rituals ... follow, more or less punctiliously, orders established or taken to have been established, by others" (1999: 32). With regard to Rappaport's distinction between 'self-referential' and 'canonical' features of ritual, discussed above, we can ask what elements of modern biomedical routines surrounding mechanical help-heart implantation can be regarded as 'self-referential- and which as 'canonical'? The aim of these rituals is to use knowledge and technology to save lives, at the same time as status positions and roles are established and distributed, accompanied by a whole set of new privileges and obligations. The actors are hence divided into the sick and the curers, the laymen and professionals, the representatives of institution and patients and their kin. The relations are established – especially the existential relation of 'trust'. Technology represents 'hope' for the hopeless while their trust is invested in the expertise of the experts. Expectations are raised, perspectives are contested. This highly dynamic flux of 'self-referential' communication is, however, inevitably suspended in the wider web of meaning on which the entire logic of implantation practices rests. This is what Heartisans themselves would refer to as

'the objective truth', i.e. the nature of things as defined by natural scientific paradigm. This outlook, the biomedical take on things, is the very 'canonical' message of these practices. This is where it gains meaning, logic, and validity.

The theoretical discussion of ritual presented here suggests that all formalized practices can be said to contain some ritual aspects, be it their instrumentality, their repetitiveness, their importance, their formal and structured character, their ordering power, their habitualizing power, their communicative power, their celebratory quality, their air of secrecy, their dramaturgical performativity, or their aesthetics. So an analytical distinction can be made here. First, biomedical clinical practices can be described simply as strictly instrumental. Their explicit aim is dealing with diseases, injuries and defects in humans. Second, they can also be described as communicative in that they are strongly linked to a given social order, to professional identity, and to change or transformation ("the sick" are being treated to become "the healthy"; the "defect" is being treated to become "the restored"; "the broken" to become "the repaired"). Third, they can be described as formalizing or 'ordering' in that they provide normative manifestations of their own ontological grounds. This distinction, to all intents and purposes analytical, provides us with glimpses of culturally specific sensibilities from which these biomedical clinical practices can be appreciated with the emphasis on their non-instrumental (communicative, ordering, expressive, symbolical, aesthetic, emotional) aspects which allow us to recognize them as rituals.

In conclusion, I will stress the importance of ritual theory for unlocking the non-instrumental aspects of modern biomedical healing rituals. In this thesis I assume that ritual practices of treating the patients suffering from advanced heart failure are the "acoustic mirror" (Denzin 1997: 25) in which Heartisan culture resonates as an embodied, subjective, understanding among the performers. In other words, clinical rituals are where Heartisan culture have reciprocally been made and proclaimed. It is in these rituals that lived clinical

reality of dealing with disease, body, life, and death as properties of the ‘objective’ world of nature merges with the postulates about the true order of things of this ‘objective’ world, the natural laws.

Ritual in institutions

For the sake of comparison Turner refers to Goffman and to the “characteristics of total institutions” that he accounts for in his book *Asylums* as an example of monastic, military, and mental institutions in which the ritual practice of de- and reconstruction is shown (Goffman 1961). Although Goffman makes rather minimal reference to these practices as rituals (he does so elsewhere) his focus on institutional practices brings us back to another familiar topic – the rituals in clinical institutions. The idea of looking at the contemporary biomedical and other technoscientific and health-related practices through the lens of a ritual is nothing of a novelty. Besides Goffman, many other scholars have made use of the concept of ritual in general, and of liminality in particular, when studying these kinds of practices. Surgeon Berkeley G.A. Moynihan portrayed surgical operation as a ritual emphasizing the necessity of painstaking preparations and attention to details as essential of the good “merciful art” of surgery (Moynihan 1920). Robert N. Wilson wrote about teamwork in the operating room as ritualized drama marked by a general sense of awe, non-verbal communication, religion of competence and possibility of creativity and innovation (Wilson 1954b). Obviously inspired by the work of Goffman, sociologist Philip Strong has studied the ceremonial aspects of patient-doctor interaction (1979). Charles Bosk explored occupational rituals in hospitals that help clinicians manage uncertainty, make decisions, and evaluate outcomes (1980). Bosk concludes that these rituals, while being increasingly challenged by the growing flood of information-processing capacities of modern medicine, remain essential to clinical practice reminding physicians that “... doctoring is human work ...” (Ibid: 76). Pearl Katz has looked at surgical rituals in the operating room (1981; 1999). Paul Atkinson writes about the “liturgy of the clinic” as he describes the

ceremonial forms of various clinical practices in the hematology department as an important tool for joint creation of medical knowledge (Atkinson 1995).

Works by Hugh Gusterson and Susan Merrill Squier will suffice as examples of studies of institutionalized rituals outside the hospitals. Gusterson examined nuclear tests performed by weapons scientists as rituals (1996). Squier used the concept of *liminality* and *liminal lives* to explore how practices like the biomedical and biotechnological assisted reproduction, stem cell research, and transplant medicine create liminal lives that in turn are a perfect fertile soil for further growth of biomedical and biotechnological dreams (2004).

The argument I develop in this thesis will be illustrated with reference to ethnographic data. Everyone going through a biomedical health care system is, in some sense, undergoing a rite of passage. The concept of liminality will for the most part be used for analysis of 'long-term' healing rituals where the patient is hospitalized and provided with a room, bed and hospital gown. By entering the hospital world, each patient is being separated from the familiar context of his or her everyday life. During the treatment they are in the midst of the transition, i.e. "betwixt-and-between"; neither here nor there. Ultimately, the explicit purpose of treatment is to cure and in doing so to optimize the patient for reintegration – return to his or her life. This is accomplished by discharge after successful treatment.

PART II

PART II of this thesis consists of three empirical chapters which are organized so as to correspond to the tripartite chronology of *rites of passage*, as outlined by Van Gennep and Turner (1997[1969]; 1960[1908]). Drawing from gathered ethnographic data, the three empirical chapters follow the succession of the practices in mechanical help-heart treatment (see Figure 1). Thematically, however, they revolve around the creation and maintenance of hope as the most central aspect of mechanical help-heart treatment.

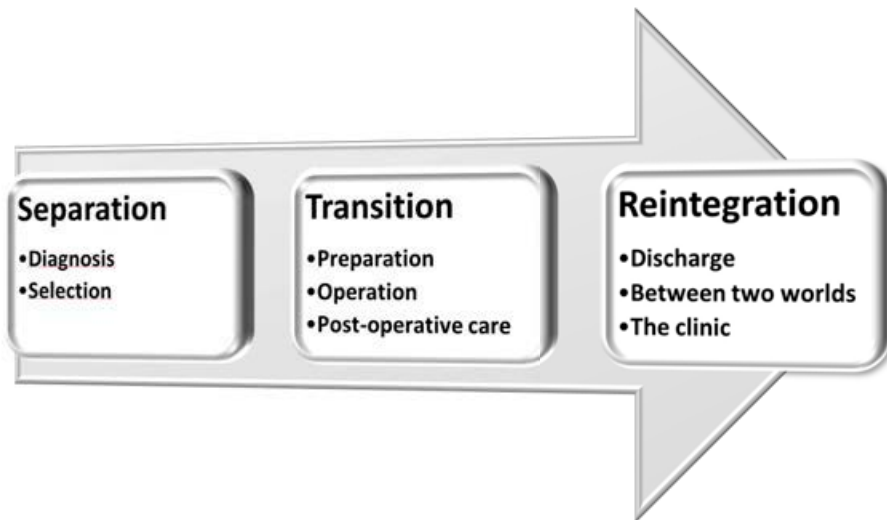


Figure 18: The succession of practices that constitute the three stages of mechanical help-heart treatment

In the first empirical chapter, CHAPTER FOUR – SEPARATION, I provide a comprehensive outline of standardized practices through which a patient is diagnosed and selected for mechanical help-heart treatment. The certainty and imminence of death as one of the main criteria required for a person to be selected renders this particular treatment and technology as the only hope. During the separation

stage a patient is, through the filters of hospitalization procedures, being *separated* from his or her regular everyday life – what Turner refers to as rites of separation (1997[1969]). Furthermore, a person is also gradually ascribed a new, temporary, identity – a person with a failing heart becomes an end-stage heart failure patient. This means that a person is being integrated into Heartlands culture – he or she is temporarily turned into a Heartisan.

In the second empirical chapter, CHAPTER FIVE – TRANSITION, I account for practices surrounding the surgical implantation of a mechanical help-heart, including preparation, operation, and post-operative care. The practices of preparation lay the foundation for hope, indispensable for the success of the treatment. During this stage the patient is hovering between hope and uncertainty, promises and risks, life and death, body and machine. The patient no longer holds the status position of his or her former nor future self. Thus, the patient is liminal in a sense that he or she is in the middle of disruption of his/her regular life, neither here nor there, in-between two structures. Hope, enacted as the essential counterpoise to the threat of death, goes beyond being merely the inherent quality attributed to this particular kind of technology; it becomes the very prerequisite of its success and is therefore treated as a virtue. Thus, creation and maintenance of hope is provided a central place in this stage of mechanical help-heart treatment.

In the third and last empirical chapter, CHAPTER SIX – REINTEGRATION, I focus on the person's return to his or her ordinary life at home as a new, 'saved', person and also on the role of the clinic in this process. Contrary to the reintegration being a completion of rites of passage, the reintegration of the mechanical help-heart patients turns out to be quite unique – by leaving the hospital the patient's place in the Heartisan community is lost while his or her newly acquired patienthood turns out to be permanent. No longer a Heartisan, yet still a patient, not quite healthy nor really ill, no longer hospitalized, yet still not quite ready for the life outside the hospital, a reintegrating patient is still liminal. The ambiguity of

tension created by the juxtaposition of dualisms which permeate the stage of liminality – uncertainty/hope, risks/promises, sickness/health, life/death, and machine/body – is bound to continue while the patient hovers in the social blind spot in between life in the hospital and life at home. In other words, the patient's liminality is open-ended. Instead of just providing the means of salvation, mechanical help-heart patienthood becomes one.

With the implantation of a mechanical help-heart, the social, cultural, and emotional aspects of being human are contested in a new manner. These implications of implanted technology bring about a new mode of existence. Instead of reintegration to a regular daily life, a person lingers in a social blind spot between two worlds, while his/her life is put in the continuous loop between uncertainty and hope, risks and promises, life and death, machine and body, irretrievable past and uncertain future.

CHAPTER FOUR – SEPARATION

Separation is the first stage of mechanical help-heart treatment, and refers to a group of practices through which a person is separated from his or her former life at home and initiated into a hospital life in Heartlands. This group of practices effectively categorizes the sick person as a mechanical help-heart patient, providing him or her with a certain place among other Heartisans.

As heart failure is a chronic illness, the encounters with medical experts are bound to be repeated – each encounter adding further strength to a process of building the sick person’s new temporary social status. This temporary status is that of a ‘mechanical help-heart patient’ that will help the sick person through the clinical treatment and to a more permanent status of the ‘healed’, ‘restored’, or ‘saved’. The initiation into this particular patienthood necessitates separation of sick person from the familiarity of his or her everyday life and assimilation into an unfamiliar new context of the hospital. This means that most of the old rules, social and cultural codes, and daily routines are substituted by, or are made subordinate to, the new ones⁷⁴. Separation is carried out through a series of formal evaluative practices, the instrumental aim of which is, first, to diagnose and then to select the patient for this treatment.

In sum, separation is made up of two larger groups of practices: *diagnosis* and *selection*. Diagnosis practices aim to identify the patient’s condition, its underlying causes, and the way it is progressing. They are ordered in a sequence of three stages, including i) anamnesis (recollection practices), ii) physical examination (observation practices), and iii) technological examination (revealing practices). Selection practices deal with evaluation, classification, and selection of patients with reference to the earlier established diagnosis and the discussions regarding the fitting treatment. They are ordered in a

⁷⁴ See also the account of admission procedures in CHAPTER FIVE – TRANSITION (pp 240).

sequence of two stages: i) evaluation (assessment and prognosis practices); and ii) discussion meetings (medical expert discussion practices). Hence a general overview of practices of separation can be presented like this:

1. **Diagnosis:**

- a. anamnesis
- b. physical examination
- c. technological examination

2. **Selection:**

- a. evaluation
- b. discussion meetings

The sequential order of these, or any other formalized practices in Heartlands, is an empirically and analytically identified pattern of key practices that should by no means be mistaken for a literal representation, i.e. a rigid template, of all clinical practices. Like any other elements of social and cultural life, these established formalizations, rules, customs, and organizational frameworks are in continuous flux. Their chronology is sometimes irregular; sometimes they overlap, coincide, or collide, they may run in loops, their succession is at times interrupted, and at other times delayed or prolonged. All of this is due to the influence of: 1) physiological and/or technological imperatives (such as sudden turns in health status or certain requirements of technological equipment or its malfunctioning); and 2) a variety of individual and collective improvisation and creativity (for instance inventive maneuvers, personal choices, interpretations, lateral thinking). Hence, the purpose of the sequential structure outlined here is not to generalize and force the vibrant and volatile dynamism of Heartlands into a narrow and simplifying frame. Instead, it is to, grounded in empirical data, identify, outline, and highlight a blueprint of central formalized practices that serve as a grid for the medical treatment of people with advanced heart failure.

DIAGNOSIS

“Selection of the patients is the most important thing”, said Doctor Emil, one of the Heartlands anesthesiologists, while explaining that no one can live forever with a “car engine” inside his or her body. “God the Father made us by a stroke of genius” he stressed, adding that, “we work against the clock here... no more than fifty percent of our patients survive and we shouldn’t thump our chests so proudly because these numbers haven’t changed”. While saying these words Emil grabbed a pen and started drawing a sketch of how trajectories of mechanical help-heart treatments might look and which different paths they might take. After the initial trauma such as a sudden heart attack, a patient is primarily treated with drugs, which Emil still think is the only way to actually help increase the blood flow. This is something that, according to Emil, various pump systems cannot achieve because all they can do is keep the blood flow steady. If the drugs won’t work the best option would be to put the patient on a waiting list for heart transplant. But in many cases this is not an option because a patient might be too weak to survive such a tough surgical procedure and perhaps, also, because he or she might be running out of time. The worst-case scenario is when a patient is not suited for heart transplantation at all because of a history of malignancy, for instance. For all these cases the only option available is mechanical. First, short-term pumps such as Intra Aortic Balloon Pumps or catheter-mounted heart pumps are used. If they can’t help, then long-term mechanical devices are used. Seventy percent of these patients, however, end up dying, he said. Some, although it is extremely rare, might actually get their cardiac function recovered, and then the pump is explanted. The rest are either destination therapy patients who must live with their pumps for the foreseeable future, or heart transplant candidates who are depending on their pumps until there is a heart available for them. Technically, Emil

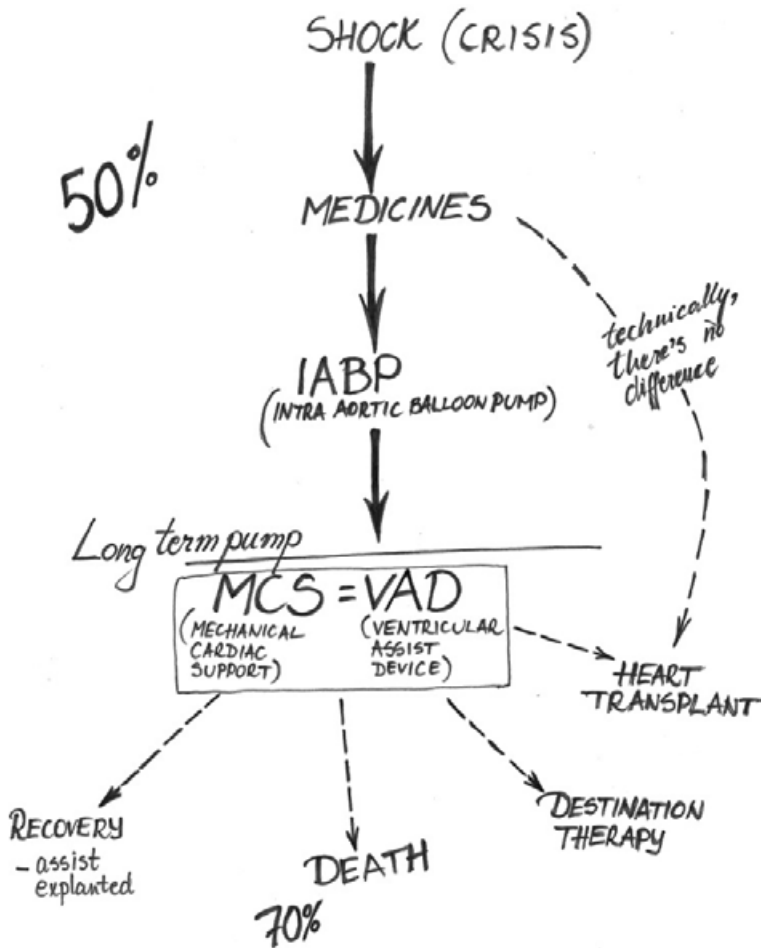


Figure 19: Reconstruction of a sketch of end-stage heart failure treatment trajectory made by a Heartisan anesthesiologist.

concluded, there's no difference between these patients and those that get to the transplant without the pump.

The selection that Doctor Emil was referring to consists of diagnosing and selecting the patient for the treatment. There are many entries into the Heartlands, and obviously, a number of different exits as well. Each trajectory eventually leads to a certain kind of treatment, a certain kind of patienthood, and a certain kind of outcome. Which

one it will be, for any individual patient, is by and large a matter of indeterminacy. Therefore, it is made into a series of standardized attempts of control by medical staff through rigid procedures, regular formalities, established rules, and customs. This plurality of processes of standardization and/or of contextual adjustment will be presented and analyzed here as a particular set of ritual practices – *rites of separation*.

ANAMNESIS

One morning, during a coffee break, one of the Heartlands chief cardiologists described anamnesis as something that needs to be “taken” more than once, as it is not certain that a patient will tell the same thing each time. Sometimes the patient forgets certain things, he said, or doesn’t think that some of the information is relevant. A young medical student sitting at the same table concurred and shared a story from her time as a student in the USA. An orthopedist had diagnosed the patient and put him on a list for operation. However, on the day of the operation the anesthesiologist happened to take an anamnesis of his own, concluding that the patient’s problem was not at all orthopedic but neurological. “Think about it!” the young student said, “He was so close to being operated on – unnecessarily”.

By anamnesis (*anamnes*), Heartisans refer to patients’ own – subjective – accounts of the state and progress of their health/illness. This is where patients get to express how they experience their condition and the circumstances surrounding it – what Heartisans refer to as ‘symptoms’ (*symptom*). Symptoms are different from ‘signs’ (*teekken*). Signs are any ‘objective’ indications of a disease, such as blood in the stool, swollen legs, or skin rash. They can be observed and recognized by anyone, including a doctor, a nurse, a patient, or his/her relatives. Symptoms, on the other hand, denote those aspects of the patient’s health/illness which can be observed, experienced, and recognized only by the patient him- or herself. These may include fatigue, pain, allergies, anxiety, what a patient can and cannot do, feelings of coldness, light-headedness, dizziness, sleepiness, thirst, or

nausea. Thus, symptoms are in Heartlands usually regarded as subjective experience and anamnesis as formalized subjective account of that experience. Through anamnesis, symptoms are situated in patients' stories about the events during which symptoms usually occur, or when they have noticed changes for the first time that caused them or their relatives, friends, or colleagues concern. Thus, anamnesis provides context of everyday life to symptoms. These stories are in Heartlands generally regarded as significant information that might reveal important facts linked to a patient's physiological condition.

In the Encyclopaedia Britannica Online (Encyclopaedia-Britannica 2010b) anamnesis is described as a "ritual of recollection". Anamnesis is "... a recalling to mind, or reminiscence ... often used as a narrative technique in fiction and poetry as well as in memoirs and autobiographies"(Ibid). Under the topic of "myth", the same encyclopedia describes anamnesis as a "... 'commemoration' or 'recollection,' ... one of the crucial parts of the Christian celebration of Holy Communion. Through the anamnesis, the Passion and death of the Lord is 'applied' to the congregation" (Encyclopaedia-Britannica 2010c). Thus, anamnesis is a joint act of maintenance of the memory of past events.

Furthermore, according to the Online Etymology Dictionary, the term anamnesis is a Greek word for "remembrance", derived from the noun of action *anamna*, stem of *anamimneskein* "to remember" (Harper 2008). So, it is a story of which the explicit purpose is to recount and preserve certain sequences of events from the past. In Heartlands it is a practice of recollecting the "crucial parts" of a patient's illness experience. It is usually referred to as something that a doctor is supposed to "take" from the patient (*ta anamnesis*). Moreover, it is not confined to the initial encounter with the doctor but is taken and re-taken over and over again for as long as the person is considered a patient.

Formal order of anamnesis

During one of the routine morning work rounds at the Heart Failure Ward, Arvid, a chief doctor, was taking anamnesis from Ann, a chatty woman in her late fifties, starting with a routine question: “How do you feel?”. “Better”, Ann answered while pointing out: “I sleep well, eat well and feel no pain”. However, she complained about pressure in her chest that troubles her whenever she eats. Doctor Arvid acknowledged Ann’s complaint with a nod and a “Yes!” and urged her to tell him about what she does. Ann then told a story about being unemployed for a while and how things took a sudden turn when she started as an apprentice somewhere – a position that she experienced as “a huge change” and “very stressful”. Ann also told a story about “quarrels” with the employment office and about how she got herself a horse, which she found to be demanding and more troubling than she expected. Without responding to Ann’s story, doctor asked if she has been treated with any heart medicine before. She had taken some diuretic pills in the 90s, she said, but was not sure if she’s been taking them since then or not. Answering the doctor’s question, Ann went back to telling her story. She managed to fall from a stool, she said, confessing that she is “a bit clumsy”. The doctor turned to the nurse standing next to him and prescribed 4ml of Furix [diuretic] for the patient.

Considering Ann’s complaint about the pressure in her chest, the doctor responded with a “Yes”, denoting an “information noted” kind of sentiment. However, Ann’s story about being unemployed, about the stress she experienced with sudden changes in her life, about quarrels with the employment office, about the work load that she is experiencing being a horse owner, and about falling from a stool and being clumsy was met with no observable response, nor was it mentioned again during the subsequent talks among the staff. What is particularly interesting here is the kind of response and the structure and type of the doctor’s questions. Instead of responding to Ann’s story Doctor Arvid changed its course tactically with a question

about her medication. Ann's story might have been noticed but it nevertheless remained unrecognized.

Not all anamneses are performed this rigidly. They may vary from day to day and depend quite a bit on the individual doctor and/or patient – or on the situation. Some anamnesis rituals may even emphasize the patient's private life and his or her hobbies. This is nevertheless very unusual. What is typical of anamnesis, on the other hand, is that its structure transforms the *person with failing heart* into a *heart failure patient*, where all the personal idiosyncrasies and the qualities of the self, as well as emotional and sociocultural aspects of the patient's illness experience, are strongly overshadowed by those aspects that are considered clinically relevant. These can include diet habits, physical activity habits, sleeping habits, "bad" habits of smoking and drinking, reactions to given medication, as well as the clinically interesting symptoms mentioned above, such as fatigue, pain, allergies, anxiety, what a patient can and cannot do, feelings of coldness, light-headedness, dizziness, sleepiness, thirst, or nausea. Subjective, emotional, and sociocultural aspects of illness experience are downplayed by the way in which anamnesis is structured.

In spite of the rhetorical emphasis frequently used to depict the patient as the exclusive author of anamnesis which is then 'taken' by the doctor, the shape and content of the story thus obtained is, however, not completely a property of the patient's own creative effort. Instead, the way this practice is structured also structures the shape and character of what is taken. There are certain conventions in Heartlands determining what qualifies as relevant enough to be included in anamnesis and what doesn't – criteria grounded in the mechanistic concept of illness characterized exclusively in terms of quantifiable facts of natural sciences. The patient is not expected, and often not allowed either, to speak of whatever he or she thinks of as important. These conventions are apparent in the way anamnesis is performed. There seems to be an agreement among the Heartisans regarding the significance of these principles. Patients are carefully instructed to abide by them. Through the mere formalization of the

way anamnesis is performed the patients are being socialized in how things are done the Heartlands way – the ‘proper’ way.

At the beginning of every anamnesis the doctor usually takes the lead. This dominant leading role is then easily upheld throughout the entire encounter. Normally, the straight-forward questions about intimate matters are launched towards them in an even flow, signaling that they are in a situation where they are subjects of investigation. The directness of the questions keeps at bay any obstacle or intimacy barrier to this particular inquisitiveness. Whatever was private outside the Heartlands is now, within the Heartlands walls, made into a collective concern. What was once personal is now made communal. Thus bloated, the patients are being deprived of their socially-built integrity-firewalls. Consequently they abide by the new rules; they answer the questions compliantly, take off their clothes, disclose delicate personal information, and lie down and sit up when told to do so.

Anamnesis is performed like an oral questionnaire which, besides acquiring the information needed for medical purposes, also tailors the story and thus prevents the patient from talking about things that the physician might consider irrelevant. Such uninvited information is usually believed to be an additional burden to the already limited time at everyone’s disposal. Any such initiative from the patient is, if regarded by the doctor as outside the field of biomedical interest, at times acknowledged and listened to but is more often either merely tolerated or sometimes even stopped and dismissed as irrelevant or simply not responded to at all. Thus, the formal order of anamnesis is implemented by doctors through their way of posing concise routinized questions and providing standardized responses that cut and tailor the shape of anamnesis according to the customary Heartisan fashion.

The most common questions when anamnesis is taken in Heartlands revolve around the patient’s ability to walk prior to falling ill and after falling ill. That is, how far the patient is able to walk now and how that relates to his or her walking ability before seeking

medical help. In addition, the physician usually asks questions about exercise, sleep, breathing, pain, stool, eating, and ‘social background’⁷⁵. The main theme of anamnesis seems to be a comparison of the patient’s present condition with the way things were before illness. This way a doctor can correlate this comparison to the time-span variable, i.e. to the length of the period of time that has passed between these two pictures – an attempt to estimate the character of the disease and the way it is progressing. However, the way this practice has been formalized into the ordered scheme of proper questions also reveals the character of the relationship between doctors and patients as well as what is valued as important in Heartlands.

One morning, during the morning work round at the Department of Cardiothoracic and Vascular Surgery, Fredrik, a young surgeon, a nurse and I walked into a room and approached Stina, the patient lying in bed number 2. Stina was looking forward to going home the following day but her blood test showed high levels of potassium (hyperkalemia). Answering the routine question “How do you feel?” posed by Doctor Fredrik, Stina complained about not finding any peace of mind and that, although she maybe felt alright “physically”, she felt bad “mentally”. Her words were met with no response at first. After a couple of seconds, Doctor Fredrik finally said that there was no reason to believe that there should be anything wrong as long as she is eating and drinking as usual. Apart from this brief response, which appeared an attempt to calm the patient by reference to clinically observable facts that should render her anxiety groundless, Doctor Fredrik said nothing about the subject of mental aspects of enduring the illness that the patient had raised.

In this example, the patient raised the subject of her concern about her mental state, which was obviously something beyond Doctor Fredrik’s expertise as a heart surgeon. Although he

⁷⁵ ‘Social background’ is usually only used for information regarding the patient’s marital (civil) status (*civilstånd*), i.e. whether he or she is married or living together with a partner or with relatives.

acknowledged her worries and recognized them as real, he also said that they were unfounded in the light of her clinical signs and symptoms. Thus, in an apparent attempt to provide hope and comfort to a worried patient, the doctor gave her instructions on what is and what is not reasonable to believe from his professional point of view— a conclusion that was in this case expressed as a general rule.

On another occasion, during the morning work round at the Heart Failure Ward, young Doctor Kent was taking an anamnesis from Fanny, an older woman. From the very beginning and during the entire course of the anamnesis Fanny tried to talk about her problems at home with her husband, who was newly retired and who, according to her story, was not taking good care of her. Instead he fed her sleeping pills, she said, so that he could do whatever he wanted to while she was asleep. At the same time as Fanny was trying to make the doctor pay attention to her problems with her unsympathetic husband, the doctor was trying to make her disregard this story as irrelevant and pay closer attention to a real problem: “Fanny...”, he admonished her, “... the one most important thing is for you to get out of the bed. You should not think about your husband now. You must think about yourself and it is completely unacceptable for you to stay in bed because it wears down your body”.

While the patient talked about her troubling domestic relations the doctor was not only avoiding the subject, but instructing the patient to avoid it as well. He persistently highlighted the importance of physical activity as the only relevant topic for the moment. Throughout the entire anamnesis the doctor and the patient talked at cross-purposes. What makes it even more interesting is the fact that the doctor obviously heard what the patient was saying but he simply treated it as irrelevant and instructed her to do the same.

In sum, in Heartlands, just as described above in the Encyclopedia Britannica Online, anamnesis is a formalized practice of recollection of patients’ experience obtained through the joint

effort of the doctor and the patient. The doctor is usually the one who is in charge of the situation, enforcing the order that is determined beforehand – the way things are done in Heartlands. Anamnesis allows, through its formal structure, for joint recollection of a patient’s life story and also for operational standardization of this practice. However, through order and standardization it is also ‘recollecting’ and thus reinforcing something else. It puts into effect and strengthens the concepts of:

1. Significance – what counts as significant/relevant and what does not
2. Conformity – what is the proper way in which these stories should be told
3. Knowledge – who asks what kind of questions⁷⁶ and who gives what kind of response⁷⁷.
4. Power – who is in charge of situation (and who therefore is responsible for implementation of given cultural norms), and who is not (and who therefore is expected to comply).

Anamnesis after anamnesis

What happens with anamnesis after it has been taken from the patient? Usually, it is audio-recorded as medical epicrisis (*epikrisis*) by the doctor and transcribed by his or her secretary. These transcripts are then added to the patient’s journal archive. The following example is a note made in the journal of a heart failure patient:

Anamnesis: Woman with known dilated cardiomyopathy. Last year deteriorated both subjectively and objectively measured as VO₂ cycling where oxygen

⁷⁶ Doctors’ questions are concise, investigative, intervening and often imperative whereas patients’ questions are usually submissive and express their dependence on guidance.

⁷⁷ Patients’ answers are usually categorical [yes, no, this, that] or descriptive whereas doctors’ answers are often analytical, instructive, turned into counter-questions that are often rhetorical or at times completely indifferent to the question posed.

uptake decreased from earlier 22ml/kg/min to 16 ml/kg/min. Echocardiogram has also showed a somewhat increasing dilation of left ventricle. Has been receiving biventricular pacemaker treatment since 0407. Patient has worsened even more during the summer. Recent weeks has not been able to walk as she could before. She used to walk with canes but has now been forced to stop after 10-15 meters last couple of days and sometimes after 50 meters. No obvious leg-swelling or weight increase. After telephone contact decision has been made to admit the patient to the hospital as a half-emergency (*halvakut*). (Patient Journal notes)

This record mentions the subjectively experienced manifestations of the patient's heart failure, yet it is surprisingly dominated by the doctor's own perspective with reference to various clinical tests, measurements, clinical history, other clinical data, and signs 'observed' through physical examination. Here is another example:

Anamnesis, clinical data⁷⁸:

Woman with image of a dilated cardiomyopathy, is being investigated with aim of heart transplantation, but in connection with this investigation a spread bilateral lung-abnormality is observed with CT Thorax. Images have been displayed for lung-colleagues [doctors] who recommend Spektramož, and she has now been treated with it for 14 days and will now be admitted for new CT Thorax, approximately 4 weeks after the beginning of the treatment. Grateful for evaluation and comparison with previous examination. (Medical consultation letter)

⁷⁸ This kind of record is different from the one showed earlier in that it is a medical consultation letter sent from a cardiology specialist to a radiology specialist, whereas the former one is a part of Patient Journal notes. This heading of the field "Anamnesis, clinical data" opens up for the clinical perspective to be included into that of anamnesis.

This example, together with several other similar ones, shows that the anamnesis such as it has originally been performed is almost completely absent. Consider, the following example:

Anamnesis:

15th annual control after heart transplantation due to the dilated cardiomyopathy, HeartMate[®] treated before that. Cardiologically healthy [*välmaende*], but has weakened lung function due to the problems with diaphragm and was for a while dependant on oxygen, perhaps not any longer (?). Due to the serious difficulties during invasive examination we have ever since decided to refrain from it. (Medical consultation letter)

This is a medical consultation letter which shows literally no signs of the original anamnesis. Perhaps there is a trace in the statement that the patient is “cardiologically healthy”. Nevertheless, this is a highly ambiguous formulation and it is unclear whether it is based on the patient’s own – subjective – account of feeling well regarding her heart or if it is based on clinical – objective – data.

In all of the examples shown above, as well as in most others that I have looked into during my time in Heartlands, the original anamnesis (patient’s subjective account) has, after initially being shaped and directed through the ritual performance of taking anamnesis, been enclosed in another, paramount, anamnesis (the doctor’s objective clinical account). The order of significance, conformity, knowledge, and power has been ritually established once again.

PHYSICAL EXAMINATION

On a morning work round in the Heart Failure Ward, Chief Doctor Arvid, followed by Doctor Tosun, Nurse Jenny and I arrived at room where two patients were lying in their beds. Doctor Arvid turned to

the patient lying closest to the door: “How are you doing?”. “Good”, said the patient. It was quite clear that he was having breathing difficulties and it seemed as if talking was quite a strenuous task for him. Stammering, he managed to say that he planned to go home today. Doctor Arvid questioned the patient’s intention, “Well, we’ll see if your body thinks so too!”. The patient responded immediately and resolutely, “Yes, it does, definitely!”. “Shall we listen to what it has to say then?” said Doctor Arvid while taking out his stethoscope.

Bodies talk in Heartlands. They have opinions and can be asked for advice. To look for the clinical signs, in addition to asking the patients, doctors turn to asking the bodies. Bodies are asked in two ways: 1) through physical examination as in the example above, and 2) through technological examination. Physical examination is performed daily, mainly by cardiologists. It is highly routinized and nearly always follows right after or coincides with the anamnesis. It is performed as a hands-on clinical observation which is primarily anatomical and where a physician makes use of his or her sensory impressions – vision, palpation, hearing and smell. Only small parts of this particular kind of examination are performed with the help of a simpler kind of equipment such as a stethoscope, or with various devices for measuring the blood pressure or sugar level. The stethoscope is used to enhance the scope of the doctor’s sensory impression of hearing; the technology of the stethoscope amplifies the audio volume of the patient’s inner body. This is also the most common piece of equipment used during the physical examination. Use of devices for measuring blood pressure and/or a glucose meter for measuring the blood sugar level during physical examination is extremely uncommon as these two measuring techniques are part of the work done by the nurses who then, in turn, update the physician with the latest numbers. So the doctors would usually not perform these practices unless a particular case caused them ambivalence and uncertainty about these numbers.

The physical examination starts generally with *‘visual’ observation*. Everything about the patient might be of relevance – the posture, way

of walking, facial expressions, red or pale cheeks, or observable eczema. In this first stage of physical examination the physician has a chance to notice observable signs and symptoms which might be significant for making a diagnosis. During the second stage, the doctor routinely asks the patient to lift his or her shirt and then listens (*'audio' observation*) to the front side of patient's torso to examine the heart (heartbeat) and to the backside to examine the lungs (breathing). The doctor's opinion thus far is usually not revealed to the patient except for an occasional "it [the heart and lungs] sounds good". Otherwise the doctor remains silent and continues the examination according to the established rules of this practice. After listening with a stethoscope a doctor might try other methods of audio observation. One such method is percussion by finger-tapping where the doctor places the palm of his or her hand on the patient's back and taps the back of the hand quite hard. This practice is repeated on a number of different spots on the patient's back generating a specific sound as if drumming on an empty trunk – wherever the resonance gets muffled is an indicator of water-filled lungs. Then a doctor might perform *'palpatory' observation* as he or she feels the patient's pulse, either on the patient's neck or wrist, or both. This is also sometimes combined with stethoscope audition of the heart where, for instance, turbulent blood flow murmurs in the heart are observed through audition and then compared with the wrist pulse reading through palpation. Finally, further palpation is done where the doctor looks at and feels the patient's legs at the feet and ankles and between the knee and the foot looking for any signs of edema (swollen ankles, feet, legs) or poor blood circulation (cold legs). All these examination methods are done with the hope of either confirming the doctor's initial guesses (whether positive or negative) or revealing some new facts and thus opening up other possible explanations. Although the arrangement may vary depending on the personal habits of any individual doctor or on the particularity of a given situation, the sequences stated above are the order in which these steps are usually taken. After the examination is completed a physician makes an official statement

about the patient's condition and the measures that he or she intends to have taken.

In sum, anamnesis and physical examination are not clearly divided but are often combined in various ways. The exact point of where anamnesis stops and physical examination begins is often very hard to determine. What's more, there are slight differences between physical examinations and anamnesis done with the outpatient clinic patients, and those done with the hospitalized ones. With the outpatient clinic patients, a physician would normally start with anamnesis and then conclude with physical examination. Yet even here, no clear transition from one phase to another can be discerned. With hospitalized patients, on the other hand, physicians often perform both rituals simultaneously, integrating them into a one single ritual. The privacy of only one doctor examining one patient, that might occur in outpatient examinations is practically non-existent during routine examinations of hospitalized patients, as they most often also involve a crowd of other doctors, nurses, assistant nurses, patients, (and sometimes an anthropologist).

Similar to anamnesis, the structure of physical examination rituals outlines:

1. Significance – what counts as important information that the examination is supposed to reveal.
2. Conformity – what is the proper way of performing physical examination in order to reveal this information.
3. Knowledge – what kind of skills are required for interpretation of the data gathered through physical examination.
4. Power – the social order⁷⁹.

⁷⁹ Through performance of physical examination the roles among the actors are defined and ordered and hence also their action-space; there are those who examine (the physicians) and those who are examined (the patients), i.e. the doctor is the one performing the ritual while the patient is merely its subject.

As the diagnostic practices unfold it becomes clearer that all of the above-named qualities are systematically being put into effect as prerequisites for clinical creation and maintenance of hope for the ill person. They reflect the authority, use, and creation of clinical knowledge on which this particular kind of hope relies. Failure to recognize the power of this knowledge and to abide by it would pose a serious threat to the creation and maintenance of hope. Acknowledged by medical science as necessary, clinical knowledge not only renders hope a desirable emotional state in the face of adversity, but makes it the ultimate virtue. Loaded with such value, hope is incorporated in the logic of clinical practice as the aspiration that substantiates it.

TECHNOLOGICAL EXAMINATION

Today, in most developed countries, the modern hospital has emerged as the center of a technologically sophisticated health care system serviced by an equally technologically sophisticated staff.

(Bronzino 1995: iii, *The Biomedical Engineering Handbook*)

Another way to ‘ask’ the body is with the help of medical technology. Biomedical technology permeates all kinds of examination in Heartlands. In fact, apart from anamnesis and most of the conventional physical examination, almost everything that is known about the patient’s condition is observed, depicted, and organized with the help of a wide variety of medical technology. The dependence on technology is so extensive that most of the current biomedical knowledge and practice would be completely out of reach without it. This particular kind of knowledge is a grid connecting all biomedical areas to a great body of contemporary biomedicine. In Heartlands, patients are usually subjected to one or more of several technological tests and examinations, both before and after anamnesis and physical examination:

- Various types of blood tests – ordered by a physician, collected by nurses and analyzed by biomedical analysts who then report back to a physician.
- X-rays – performed by radiologists, biomedical analysts, or specially trained X-ray nurse (*röntgensköterska*).
- Ultrasound – performed by radiologists, cardiologists specialized in ultrasound, or by biomedical analysts and analyzed by radiologists and/or cardiologists.
- Electrocardiogram – performed by nurses or biomedical analysts and analyzed by the cardiologist⁸⁰.
- CT-scan – performed by a specially trained X-ray nurse and analyzed by a radiologist.
- Cardiac catheterization – performed by a cardiologist.
- Coronary angiography – performed by a radiologist.
- Stress test – performed by a biomedical analyst and analyzed by a radiologist.

In the following I will show some examples of how these examination practices are usually performed.

No “hocus-pocus”

Heartisan doctors show pride in their modern technology and refer to it quite often in a language of devotion. At the same time, they are very keen not to attribute it with any miraculous power. The language of devotion clearly denounces anything ‘magical’ about technology and emphasizes it as a logically compounded tool mastered by logical and skilled medical experts. In contrast to the obscurity of magic, the

⁸⁰ It should here be noted that most Heartlands nurses are trained in reading and interpreting electrocardiogram graphic sheets. The electrocardiogram machines are also equipped with an automatic analysis function generating few lines of text with a ‘probable’ interpretation of the electrocardiogram taken. Neither the nurses’ nor the machines’ interpretation is, however, regarded as reliable and no conclusions are usually drawn until a doctor has analyzed and interpreted the images.

power of medical technology is explicable – it is a product of science⁸¹ and therefore its workings can be logically and rationally explained.

I recall Peter, a heart failure patient in his early thirties whose condition was not getting any better; in fact, Peter was getting weaker each day. During one of his many and regular visits in Heartlands, Peter was lying on the examination bed, naked from the waist up. On his left side, Doctor Patricia was sitting behind an ultra-sound machine consisting of ultra-sound computer, monitor, loudspeakers, Doppler, and various accessories, all placed on a plastic cart. With help of this machine, Doctor Patricia was performing an ultra-sound examination on Peter. The sound of Peter's heart kept beating in the loudspeakers. Jokingly, Doctor Patricia bragged about and showed pride in this technology. Peter seemed less impressed by the sound. On the contrary, he found it rather repugnant, "It sounds like a clogged sewage system!". Doctor Patricia disagreed and said, clearly amused by Peter's remark, that the sound coming out of the loudspeakers was music to her ears. "That's it, no more butter for me!", Peter continued with his quasi-satirical lament, blaming himself and his lifestyle and taste for butter for this 'clogged sewage system' of a heart that keeps throbbing through the loudspeakers. Patricia carried on with her romantic talk about the ultra-sound picture of the heart. She turned to me, explaining the colors and shadows on the screen, describing them as "the prettiest thing you can see", laughing loudly and trying to cheer Peter up. But Peter turned out to be quite a tough audience – he didn't agree. "You find my view of beauty distorted?", Doctor Patricia shouted out teasingly, and started interpreting the pictures on the screen for us. "It is actually no hocus-pocus. It is very simple", she said, explaining that it was all about timing; the opposite sides of the cardiac wall need to be in sync with each other. "It's all about timing", she repeated and went on, "everything in life is about timing!". She was clearly proud of the

⁸¹ The fields of engineering, medicine and computing, which together comprise the domain of Biomedical Engineering.

ultra-sound machine and referred to it as “a high-tech sound and picture of the heart... no hocus-pocus”. She also showed us a mismatch on the curve chart on the screen saying that it is exactly this mismatch that represents the unsynchronized opposite sides of the cardiac wall and that this was what she and her colleague, a cardiologist and pacemaker specialist, will try to fix when he arrives – they will try to get those mismatched sides of the cardiac wall in sync with each other by tuning the pacemaker. At this point Peter turned to me and said: “Those numbers don’t mean a thing to me. I guess I’ll just have to wait and see what they [the doctors] say later on”.

Peter’s heart has been represented with the help of biomedical technology. Doctor Patricia stressed several times that there is “no hocus-pocus” in the core of utilized technology, implying that it serves to visualize the heart. The illness is hidden within the patient’s body and the ultra-sound machine provides a way to reveal it and make it sensory-perceptible as a set of images, shades, colors, and figures that are displayed on the ultra-sound machine monitor, as well as sound that comes out of the ultra-sound machine loudspeakers. Locating and identifying the condition enables doctors to choose their strategies and their weapons in an attempt to overpower the influence of illness. Thus, the potent danger of a hidden bodily defect (in this case the unsynchronized contraction of a heart muscle) is at least partially reduced as it is revealed.

This brings to mind Victor Turner’s account of the *ku-solola* ritual principle in *Isoma* ritual⁸² among the Ndembu which literally means “to make appear, or reveal” (1997[1969]: 25). The *ku-solola* principle was used for symbolical representation of the patient’s inauspicious condition, which in turn symbolizes the potency of the *Isoma* ritual and its mastery over the “hidden” (*chamusweka*) and “dangerous” (*chafwana*) condition in a patient. In the same way the Heartlands rites of revealing, i.e. technological examination, make a technological representation of a hidden and dangerous bodily defect, symbolizing

⁸² *Isoma* is a healing ritual for women who have had several miscarriages and/or abortions.

the potency of medical knowledge and technology that empower heart doctors' mastery over the disease.

Another interesting thing is Peter's comment about his cluelessness regarding the images, numbers, and diagrams that are displayed on the screen of the ultra-sound machine. He was depending on doctors to tell him what these representations mean. At the same, Peter joked about this and seemed to belittle himself before the technology and Doctor Patricia's medical knowledge, as if to assure himself that he was in good and knowing hands – the hands of a doctor who sees the meaning in these complex images and figures and who therefore can provide glimpses of hope. Patricia's reference to "high-tech sounds and pictures of the heart" also indicates her liking of this technology. "High-tech" denotes the advanced and sophisticated technological development (Encyclopaedia-Britannica 2010a; OxfordUniversityPress 2010). Mastering and interpreting such advanced and sophisticated technology requires by necessity equally advanced and sophisticated skill.

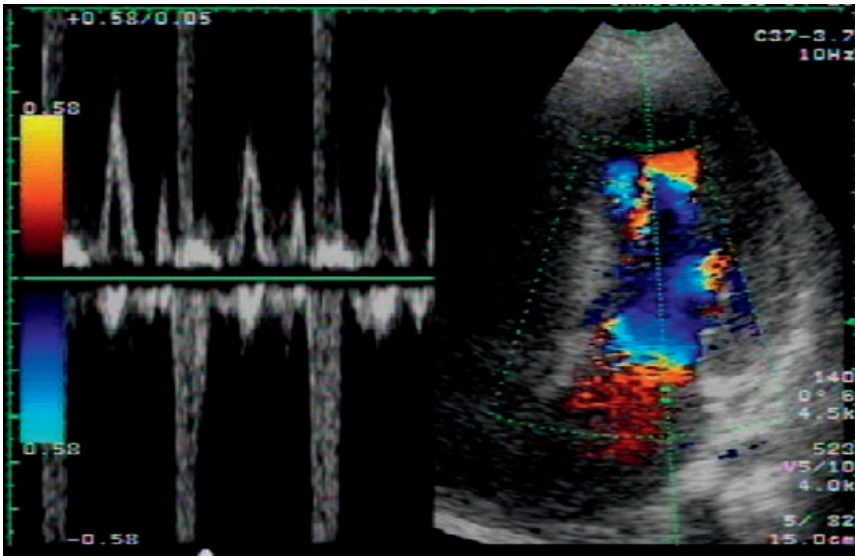


Figure 20: Ultra-sound screen-shot (source: <http://naveenballal.tripod.com/id3.html>)

Furthermore, Doctor Patricia emphasized her and her colleague's importance as fixers of the unsynchronized heart muscle. They are the ones who hold the knowledge and thus also the power required to be able to make use of the technology, to interpret the images and sounds, and ultimately to repair things. The technology is in this case being used as a documenting tool for doctors to reveal a hidden bodily defect – in this case a heart muscle out of sync – and to tune the heart technologically until it contracts properly.

Judging from this example, and also from several other similar examples of technological examinations observed in this study, the way they are performed manifest what by now is a familiarly ordered structure of:

1. Significance – what counts as important information that the technological examination seeks to reveal.
2. Conformity – what is the proper way of understanding and performing technological examination in order to reveal this information.
3. Knowledge – what kind of skills are required for mastering utilized technology and for reading and interpretation of the technological data.
4. Power – the hierarchy ladder⁸³.

Through performance of technological examinations these qualities are once again being put into effect – this time with the aim of revealing hidden and dangerous bodily defects as a part of clinical creation and maintenance of hope. Mastery of advanced medical technology serves as evidence of clinical expertise – a harbinger of hope. It is enacted as the only way to shed some light on the

⁸³ Through performance of technological examination, the roles among the actors are defined and ordered and hence also their action-space. There are those who examine (the physicians), that which is used for examination (the technology), and those that are examined (the patients). Thus the doctor is the one performing the ritual and mastering technology while the patient remains merely its subject.

unknown and thus to keep the hope of an achievable repair alive. Just as in the practices of anamnesis and physical examination, technological examination practices add to the high merit of hope as a virtue, thus confirming the key logic of clinical practice. There are, however, practices of technological examination during which the doctors are completely absent, thus granting the technology itself much more space.

Destination hope

Not only diagnostic technology, but medical technology in general, is often spoken about in a language of devotion, not least among the patients. During one of my conversations with Peter, the young patient featured in the example above, he told me about his pacemaker which he had received several years ago. It was the latest innovation at the time he received it. He might as well have been the very first patient ever to receive this particular model, he said. In fact, it was so new that doctors didn't know what to do with it, or how to attach the wires. Peter laughed and said that he found it really unbelievable how technology keeps progressing and developing. Now, the doctors were considering him for implantation of a new, modern pacemaker with defibrillator function, to replace the old one. Such things didn't exist at the time Peter got his pacemaker. He talked with awe about the Swedish man who invented the pacemaker by doing his research and making prototypes and tests with electrodes in a small empty shoe polish jar. Peter laughed again, "And look at it now! They are all tiny and everything". And then he added: "Have you seen these total mechanical hearts? It's unbelievable". Peter had seen a program about it on TV and was obviously deeply impressed and full of admiration. "It's fascinating! I hope they'll get there soon... as it is now you don't last for long with one of those. I really hope they can make it a good substitute for the normal heart".

Peter expressed hope – hope in the rescue that exists in medical technology and medical science, in the way they are progressing – the hope that exists in the near future. He found the technology and the

technological development to be “unbelievable” and “fascinating”. Technology today, it was clear to Peter, is better than it was before. Therefore, he sees the shape of technology to come as indisputably better than today’s. The trust that Peter showed in the progress of medical technology reflects his firm belief that there *will* be a rescue in the future. The only problem is whether he will live long enough, to that very point of technological development, before his heart fails completely. Peter said, “I hope that ‘they’ll get there soon” – but what is soon for Peter? What does it mean? Before he dies? For Peter it is a matter of *his* life or *his* death. Peter knows how sick he is. He also knows that things are not getting any better. He has been thinking about the alternatives. He has been dreaming about new solutions. He obviously likes the idea of technological salvation – a good engine that would substitute for his deficit... to *engineer* his heart problem away. What the concept of ‘soon’ in this context means to Peter is probably something other than what it means to me. Peter’s ‘soon’ implies something rather imminent and strong. ‘Soon’ is perhaps an expression of hope. Or of fear. Or both.

It is interesting how Peter spoke of new technology as being far ahead of the doctors – as if technology was progressing on its own. But soon enough Peter turned the praise around and directed it towards the humans behind the technology – as when he talked about the inventor of the first pacemaker or when he expressed his hopes that ‘they’ will manage to make a good enough mechanical heart before he dies.

A couple of weeks later, during another routine ultra-sound examination, Viktor, a cardiologist, explained to Peter about the defibrillator that he was about to have implanted. He warned him about the risk of a defibrillator going off with no real reason... without cardiac arrest. Peter reacted with sarcasm, “Oh, that’s great!”. “That’s why we want to discuss this thoroughly with the patient... to see if the patient wants to join the train ride⁸⁴ before we implant

⁸⁴ The idiomatic Swedish expression is “*vara med på tåget*” which literally means “to be ‘with’ on the train”, meaning *to join the train ride*. Not only does

anything”. Peter said that it doesn’t matter to him, adding “You [the doctors] are the ones who decide what’s the best thing for me”. Peter did pose a few questions about the odds of the defibrillator going off and whether that would hurt or cause any damage. Other than that, however, he pretty much accepted whatever was explained to him. It seems like there was nothing to be negotiated as Peter’s heart was so weak that he lived under constant threat of cardiac arrest⁸⁵ or ventricular fibrillation⁸⁶. Peter subordinated himself to the supremacy of the Heartisan doctors’ knowledge, leaving his fate in their hands. This reminded me of Bengt-Erik, a mechanical help-heart patient, who once said: “... how long I’ll live, I’m not going to worry about that... I’ve left that to those who know a little bit more about these things”.

It is also interesting how the idiomatic Swedish expression for “joining the train ride” (*att vara med på tåget*) anchors the patient to an already predetermined and dominant social context. First, the expression is unique to the Swedish language and there is no expression in English that can grasp its complexity. “Joining the train ride” indicates the existence of others who are already on the train and with whom one might join. In Peter’s case, the others who were already on the train were Doctor Victor and his colleagues, all medical doctors – the ones respected for their knowledge. Moreover, in combination with joining the ones already onboard, the train they’re on seems to be either already moving or about to depart, leaving the patient with the sense of being left behind otherwise. Finally, ‘train ride’ denotes a journey for which tracks have already been laid, i.e. a predetermined one-way ride – with the destination of hope. Peter seemed pretty much in agreement with wherever the train of medical science and technology was taking him.

this expression contain the notion of journey – the train rails indicate that the journey has already been staked out, that it is predestined.

⁸⁵ Cessation of normal circulation of blood.

⁸⁶ Emergency condition where the heart muscle is not contracting but trembling uncontrollably – if not reversed the patient might die within minutes.

Talking machines

Our machines are disturbingly lively, and we ourselves frighteningly inert.

(Haraway 1991)

Some of the technological examinations are performed in the absence of a customary ritual leader – the heart doctor. A CT scan, for instance, is one of such examinations where whole the rite is initiated, supervised, and completed by an X-ray nurse in the role of a ritual leader. During the central part of these rites, i.e. the actual performance of the craft of ‘revealing’, not only is the patient left on his own with the huge CT machine, but he or she is completely enclosed by it – and the machine talks to the patient.

I recall a particular CT scan that was scheduled to be performed, as usual, at the Department of Radiology. On arrival the patient was instructed by the X-ray nurse in charge of examination to lie down on a narrow flat surface that can be rolled into a huge doughnut-shaped roentgen machine that rotates around the patient while taking X-ray images. The nurse injected a contrast fluid⁸⁷ into the patient, through a peripheral venous catheter⁸⁸. Then she attached the electrodes onto the patient’s naked torso in order to enable monitoring of his heart rate. An injector mounted onto the machine on the patient’s right side ensured continuous injection of contrast solution and salt-solution. The nurse instructed the patient to hold his breath while she took the images with the CT machine, and said, “The machine talks to you so you just do what it tells you to!”

After injecting the contrast solution into the patient the nurse went into the control room behind the see-through wall, where she took pictures with a velocity of one frame per second. One out of five screens was used to monitor the examination while the glass wall enabled the nurse to keep an eye on the patient. The white shade on

⁸⁷ Contrast fluid attenuates the X-rays and thus makes blood vessels visible.

⁸⁸ The peripheral venous catheter has already been mounted at the ward just before it was time to leave for this examination – so the patient was properly prepped for it.

the screen showed the web of the patient's heart- and lung vessels filled with X-ray contrast solution. These shots were further used as a reference for three-dimensional reconstruction of what a patient's heart is likely to look like, based on the shape of the vessels.

“The machine talks to you so you just do what it tells you to”; CT scanners are in fact equipped with a recording of a human voice instructing patients during examinations. In spite of the fact that the X-ray nurse was the one navigating and supervising the ritual through the glass wall, the core communication of this particular practice appeared to take place between the patient and the CT machine itself. The patient was listening to what the machine had to say and was, prior to encountering it, advised to follow these instructions. Not only was he, through the formalized structure of this practice, forged into a subject of Heartisans' authority and knowledge, but he was now also directly subordinated to biomedical technology.

Through these practices the technology is used as if it was an actor among others. What's more, it is granted authority and power as an actor who embodies and implements the proper rules of conduct that patients are expected to comply with – a familiar normative structural grid (significance, conformity, knowledge, and power) that permeates the entire process of diagnosis. Meanwhile, patients are reduced to contrast-colored vessels and reconstructed images. All patients undergoing a CT scan are addressed by the machine with exactly the same phrases – stressing the homogeneity of the patients as well as their inferiority, or subordinate status, to the vast system of biomedical authority that rests on biomedical technology.

Technology as the oracle

Continuous development of new diagnostic methods and technologies throughout the last century has contributed to development of new ideas about how the human body should be observed, interpreted, and analyzed. In addition to the patient's testimony and physical examination, various chemical and physical principles are used to map out the human body and to provide

understandable pictures of its structures. Being built on the foundation of these chemical and physical principles, these technologies are dismantling the human body, and in the process reducing it to the sum of its chemical and physical components.

It is a highly routinized part of all clinical practice in Heartlands to look to technology for answers to most of the questions. Various machines and laboratory tests are utilized as oracles. Tests and/or examinations with some of the technologies are being requested and performed daily. For instance, after one patient had complained about the ache in her stomach a doctor responded that there's nothing wrong with her liver and that they will get in touch with the gastroenterology department to make an appointment for gastroscopy. First, the doctor made a reference to what ultra-sound technology showed, and then he announced yet another technological examination, this time with use of gastroscopy technology – an oracle that might provide the answers regarding patient's stomach-aches.

Heartisan doctors and nurses refer on a daily basis to the information revealed by these oracles: "... echocardiogram in February showed a hundred millimeter ventricle"; "... echocardiogram shows that he has fibrillation"; "There is a nice flow here, echocardiogram shows that it looks really good"; "echocardiogram shows nothing suspect"; "... we need to read in Cosmic and other databases"; "... but how does it look laboratory-wise?". What's more, the results of the examinations with biomedical technology assembles doctors in ritual rounds⁸⁹ where they display and examine these results (images, numbers, diagrams, sounds) and discuss what further steps should be taken.

This kind of biomedical technology is used for more than merely diagnostic purposes. For instance, on another occasion a chief surgeon suggested the following to his colleagues – that they should perform a thoracic CT⁹⁰ on a patient discussed for implantation of a mechanical help-heart in order to see how his heart is positioned; "It

⁸⁹ See 'Discussion meetings' section (pp 213).

⁹⁰ Computed Tomography

can be troublesome to saw up if the heart is leaning against the sternum”. CT provides cross sections and two- and three-dimensional representations of inner body structures, and is here deployed as an oracle that might reveal the precise position of the patient’s heart.

In sum, while anamnesis and physical examination are used to reveal the illness by interpretation of its manifestation through signs and symptoms, the diagnostic technology – laboratory tests and visualization technologies – (revealing practices) reveal the illness by making it visible in the form of technological representations such as images, numbers, diagrams, and sounds. These revealing practices enable:

1. Monitoring of motoric and chemical processes which are taking place inside the patient’s body providing the physician with the information upon which:
 - a. A patient’s bodily condition can be determined (diagnosis)
 - b. His/her future can be envisaged (prognosis)
 - c. Treatment can be decided and organized (drugs, operation, etc.)
 - d. The patient’s response to the provided treatment can be evaluated (responder, non-responder, improvement, contraindications, side effects, etc.)
2. Spatial mapping out of the patient’s inner body structure, providing the surgeon with the map which enables the navigation during the operation.

SUMMARY

One of the primary principles in diagnostic practices is expressed in the Heartisan concepts “to see” (*att se*) and “to hear” (*att böra*), both denoting “to observe, to make visible”. This principle is intriguingly close to one observed by Victor Turner among Ndembu people in central Africa, the one they call *ku-solola*, “to make appear, or reveal”, as mentioned earlier (pp 191). Turner makes the following observation regarding this principle:

What is made sensory perceptible, in the form of a symbol, is thereby made accessible to the purposive action of society, operating through its religious specialists. It is the “hidden” (*chamusweka*) that is “dangerous” or “noxious” (*chafwana*). Thus, to name an inauspicious condition is halfway to removing that condition; to embody the invisible action of witches or shades in a visible or tangible symbol is a big step towards remedying it. This is not so very far removed from the practice of the modern psychoanalyst. When something is grasped by the mind, made capable of being thought about, it can be dealt with, mastered (1997[1969]: 25-6).

Indeed, this is not very far from the present-day cardiologists, anesthesiologists, radiologists and heart surgeons. The inner body is made visible and put on display in the form of various images, numbers, diagrams, and sounds. In this manner an individual concern (a person’s sick heart) is made into a collective one (society’s sick citizen). The society then operates through its health specialists – biomedical doctors. The abstract illness, a nosological classification, is now dragged out from the darkness of the human inner body and put on display with the help of technology. The once intangible illness is now made into something much more concrete with all its defects, lesions, deformities, chemical imbalances, and malfunctions made visible. Regardless of whether the technology is used as a tool, if it is given the status of an actor or treated as an oracle, it is always enacted not merely as something holding the power necessary for creation and maintenance of hope but also as its very reification. Or in other words, because the hope is believed to lay in technology, the technology gives you hope.

The human body, dismantled through technological examination, is represented with technological images, numbers, diagrams, and sounds. Doctors hold the exclusive power to interpret these symbols and to make use of their interpretations – to intervene and fight the disease. By making the inherently invisible illness visible, they are also

displaying the power of their expertise over the power of the nature of illness. Medical diagnostic technology is the documenting equipment, i.e. a tool, which also is a biomedical weapon enhancing the powers of doctors. Through technological examinations in which doctors perform their mastering of the technology they are also exercising their skill to make visible and to deal with – to master – the illness itself.

Technology used in various tests and examinations further enhances the powers of doctors – it helps them reach where their eyes, ears, and hands cannot. In the mean time, the human body is viewed as a machine composed of bone, tissue, cells, hormones, enzymes, and neurons which are made perceptible through the images, numbers, diagrams, and sounds of biomedical technology. With this technology the doctors create representations and interpretations of the human body as a set of digital images, sounds, and numbers. Through biomedical examination patients' bodies are ritually submitted to the authority of biotechnological logic, language, and principles. In this practice they are also redefined – from feeling and thinking social and cultural beings to physiological systems.

II SELECTION

EVALUATION

After the health status of a person with a sick heart has been established through diagnosis, a new set of practices is undertaken – selection practices. By being diagnosed, a person also obtains the identity of a certain kind of patient (in this case a heart failure patient), which calls for practices of arrangement and selection through which patients are assigned treatments that are considered suitable. Selection for suitable treatment adds yet another dimension to a patient's new identity. Being selected for treatment with a mechanical help-heart, a heart failure patient becomes an advanced or end-stage heart failure patient. In Heartlands, an advanced heart failure patient selected for

treatment with a mechanical help-heart is generally referred to as a *HeartMate-patient*⁹¹.

Selection starts with evaluation and a thorough examination of a patient with the aim of estimating the prognosis of the way his or her illness is progressing, i.e. evaluation practices. Thereafter, final classification of the patient and decision about the suitable treatment is achieved through professional meetings, i.e. discussion practices. Decisions taken during these meetings are always consensus-based. The selection practices consist of two connected processes: 1) evaluation practices; and 2) discussion practices. In order to qualify for mechanical help-heart treatment, a patient is first put through the evaluation process through which he or she is, or is not, selected for this treatment.

The main point of diagnosis is to provide the doctors with a sufficient amount of information so that they can assess where things were and where they are now. Thus, the progression of the illness is assessed through comparison of the past with the present. Through evaluation practices further examinations are performed with the aim of assessing where things are heading. In other words, through combined practices of diagnosis and evaluation the Heartisan doctors look for the future (prognosis) in the past (diagnosis) to determine and handle the present (treatment). Evaluation is made up of practices similar to those already conducted during the diagnostic practices – only this time, they are more specific and focused based on the knowledge already provided by diagnosis. This time, the questions they seek the answers for are less general: mortality risk, progress of heart failure, possible co-morbidities, and the status of other vital organs and functions. Risk factors that are regarded as a hazard to the success of potential treatment alternatives are also identified.

⁹¹ After the brand name of the long-term mechanical help-heart called Heartmate® which is used in Heartlands. This device is manufactured by Thoratec Corporation.

Thus, the repeating loops of anamnesis and physical- and technological examinations are specially tailored to suit the specific purpose of the evaluation. The template for what questions should be asked is built upon the set of criteria that need to be met for a patient to be selected for implantation of a mechanical help-heart (see “Criteria” section below). Based on the answers gained through these practices, the doctors try to envisage the most probable future scenarios of a patient’s condition and to figure out the proper treatments to prevent further deterioration and/or to alleviate the patient’s suffering. So, basically, there are two processes taking place in evaluation practices: 1) the patient’s future is assessed, and 2) the patient’s profile is determined. This repetition of technological examinations, an essential component of the entire process of evaluation, does not merely extend the doctors’ vision spatially by enabling them to ‘see’ inside the patients’ bodies – it also extends their vision temporally by enabling them to envisage the future.

Selection, thus, refers to practices in which the potential receiver of a mechanical help-heart is evaluated and discussed in order to see whether he or she meets all the criteria that are required for this procedure. The evaluation is diagnostic and investigative and builds on information gathered through repeating sequences of anamnesis, physical examinations, and technological examinations. Information thus gathered is then summed up, analyzed, discussed, and translated into an assessment of a patient’s future – a future which then can be averted and substituted with a biomedical technological one.

Criteria

The criteria required for a patient to be accepted for a treatment with a mechanical help-heart are not explicitly stated in the 2008 national cardiac care guidelines (Socialstyrelsen). The guidelines state only that the treatment might be considered a last resort for patients with

severe end-stage heart failure (NYHA IIIb-IV)⁹² who are not responding to optimal conventional medication and who show no signs of other complicating diseases or any other condition that might pose a threat to the effectiveness of the treatment. An outline of scientific evidence upon which these guidelines are based concludes that the treatment with mechanical circulatory support (MCS), both as a temporary bridge-to-transplant and as a permanent destination therapy, is thus far marked by poor research quality and insufficient scientific evidence. This conclusion clearly portrays any implementation of MCS as a more experimental rather than established, i.e. evidence-based, practice. Furthermore, it is also described as a rather expensive treatment; whatever there might be to gain in terms of survival, ability, and improved quality of life is likely to come with a price of increased infections and thrombosis complications (Socialstyrelsen 2008a: 27-30). Apart from this, no explicit criteria for evaluation are given. Hence, I turned to Heartlands and asked Heartisans themselves about how they do the selection and what criteria they use.

I asked Physiotherapist Lea, one of the Heartisans who is also a member of a HeartMate-team, about the criteria for transplantation and implantation. Lea responded with an email referring to a lecture held by a Swedish cardiologist where the following criteria for heart transplantation are listed:

1. End-stage heart failure with survival less than 1 to 2 years
2. Limited functionality, NYHA III-IV
3. Other treatments were tried (medications/devices/surgery)
4. Quality of life is expected to increase due to the heart transplantation.

⁹² NYHA is abbreviation for “New York Heart Association” Functional Classification, according to which NYHA IIIb-IV stands for the most severe cases of heart failure where symptoms are shown even at rest.

In the same mail Lea emphasized following:

I also know that one of the very important indications is expected compliance. The post-transplant treatment is very tough. Substance abuse in the anamnesis is not good. An LVAD is put in when doctors agree that the patient otherwise is probably not going to survive until the transplantation (Personal email correspondence 2010-12-20, translated by author).

Lea also forwarded my question to Chief Doctor Arvid who, according to her, referred to the International Society for Heart and Lung Transplantation and to their guidelines as published in *The Journal of Heart and Lung Transplantation* in 2006 (Mehra, et al.). In this document it is recommended that various clinical examinations and tests are performed on the patients in order to determine the mortality risk, the progress of their heart failure, the threat of comorbidities and age (Ibid: 1030). More exactly, in order for the potential recipient of a heart transplant to be accepted, the threat of obesity, cancer, diabetes, renal dysfunction, and peripheral vascular disease should be eliminated. He or she should not be more than seventy years of age. Furthermore, the survival prognosis without a mechanical help-heart must be poor. The use of tobacco is emphasized as a peril to the heart transplant and therefore as a contraindication. Patients who are considered active substance abusers (including alcohol) "... should not receive heart transplantation" (Ibid: 1034). Ultimately a neurocognitive and psychosocial assessment is recommended for heart transplantation candidates. This includes, confirming Lea's assertion about the value of compliance, an "assessment of the patient's ability to give informed consent and comply with instruction including drug therapy" (Ibid: 1034). Mental retardation and dementia are flagged for as "possible relative contraindications". Further, the whole neurocognitive and psychosocial assessment focuses on the following four areas: i)

compliance; ii) comprehension; iii) quality of life; and iv) social evaluation. Compliance⁹³ is once again stressed here as one of the most important criteria. The following recommendation is given: “Poor compliance with drug regimens is a risk factor for graft rejection and mortality. Patients who have demonstrated an inability to comply with drug therapy on multiple occasions should not receive transplantation” (Ibid: 1034). The comprehension criterion ensures two things: i) the patient is able to give his or her consent to the treatment, and ii) the patient is able to comply with complex instructions, life-style adjustments, and a drug regimen. This means that mechanical help-heart treatment and heart transplant are exclusive privileges of those with sufficient intellectual capacity. All others are classified as unfit for these treatments. Quality-of-life is an attempt to assess the patient’s “happiness”, “well-being”, and “desire for long-term survival” (Ibid: 1034-35). Social evaluation seeks to determine whether the patient has relatives and friends who are ready to “make long-term commitments for the patient’s welfare” (Ibid: 1035). In a word, being alone or unhappy could mean disqualification.

The most essential criterion for a person to be accepted is that he or she is literally dying in spite of the efforts made by conventional medical treatments. This decisive factor is so convincing that it weighs even more than the outcome of the heart transplant evaluation⁹⁴ itself. According to ethnographic data gathered in Heartlands, if facing certain death in a short time⁹⁵ a patient might be considered for implantation of a mechanical help-heart before the recommended transplantation evaluation is completed. In fact, neither of the two HeartMate-patients that I observed during my fieldwork had the heart transplant evaluation formally completed before their

⁹³ ‘Compliance’ is a rather popular expression in Heartlands that is readily used – adopted in its English form – by all professions. This will be discussed in more detail below with reference to several ethnographic examples.

⁹⁴ The Heart Transplant Evaluation is a formalized set of clinical practices aiming to match the patient’s status to established criteria for subsequent heart transplant treatment

⁹⁵ A matter of hours, days, or weeks and up to a year or two.

mechanical help-heart treatment was initiated. The mere facts that they were dying and that valuable time was running out were enough for the medical team to make a decision. In one of the cases there were no obvious contraindications to suggest that heart transplantation might be ruled out. One such contraindication would, for instance, include any signs of tendencies to malignancy. In the other case, however, “alterations” in lung tissue were identified which doctors couldn’t figure out at first. This was examined promptly and several specialists were consulted. However, the test results and final diagnosis did not appear until after the treatment with the mechanical help-heart was already underway. It is true that doctors, based upon their experience and knowledge, did not think that the tissue alterations were malignant. Still, had these hypotheses been sufficient for a reliable diagnosis the biopsy test wouldn’t have been looked into in the first place. The fact that the patient was labeled as dying outweighed the significance of uncertainty caused by these lung tissue alterations. This implies that there was a certain risk – even if slight – that the patient might have, after receiving a mechanical help-heart, been forced to confront the fact of not being accepted for heart transplantation. At the same time, the doctors feared that the patient would probably die if the implantation had been postponed until the arrival of formal test results. Both patients were well aware of the fact that they are being subjected to heart transplant evaluation. The risk of not being accepted was, however, not addressed explicitly before the patients nor discussed with them thoroughly. Officially, they were labeled as “preliminarily accepted for heart transplantation”.

It was during the implantation of her mechanical help-heart that lung- and heart biopsies were taken from Maja, the patient with mysterious tissue alterations, in order to find out whether the samples showed sarcoidosis⁹⁶ or any signs of malignancy. The patient had repeatedly expressed her worries regarding her heart transplant evaluation and the biopsy results. Results were, however, late. On one

⁹⁶ A non-malignant formations of the cells into nodules in certain organs, most commonly the lungs.

of the regular work rounds Maja expressed her interest in biopsy results and asked Chief Doctor Arvid how far her heart transplant evaluation had come. “It is not completed yet”, he said, instructing her that she shouldn’t worry as the point of this treatment is that the patient should gain something from the implanted pump. He also added, “... you gain some time during which you can get stronger, build up some muscles, and get in the best shape possible in order to get through such a tough operation as a heart transplantation”.

The answer of “It is not completed yet” acknowledged and directly answered Maja’s question. However, the doctor didn’t inform Maja any further about the implications that this answer might have for her. Nor did he provide her with any update of the discussions that had been taking place among the colleagues lately regarding her transplantation evaluation. Instead, he somehow steered away from the topic of uncertainty, which the absent biopsy results inevitably bring about, to the topic of what the purpose of the mechanical help-heart is. Clearly, he was using this strategy to provide Maja with hope and comfort – or at least not to scare her or add to her burden of anxiety. Hope seems to be regarded as necessary for the success of the treatment, as absence of hope is treated as direct contraindication. Could it be that the proper amount of information required for the proper way in which informed consent should be acquired is something of a practical contradiction? Is there such a thing as information overload that would counteract the obligation of medical professionals to provide the sense of hope and safety? Is this an example of a deadlock regarding some principal ethical considerations in these kinds of situations?

Seven days later, the biopsy results were still absent. At 09.20 in the morning Chief Doctor Arvid had not yet arrived in the ward and young Doctor Jessica was waiting for him together with Nurse Ebba in the nurse’s reception so that they could start with the morning work round. Physiotherapist Lea was also there talking to us. She had heard that doctors were still waiting for the biopsy results. “We don’t know whether this will be destination or a bridge”, she said and

Doctor Jessica added that they will know more next Thursday as the cardiologists had scheduled a discussion meeting with the lung department.

What Lea insinuated was that if the results of the lung biopsy should show signs of malignancy, Maja would not be accepted for heart transplant. Consequently, her HeartMate-treatment would then be redefined from bridge-to-transplant to destination therapy, meaning that her mechanical help-heart would be a permanent solution. Doctor Jessica did not oppose Lea's insinuation, thus acknowledging destination therapy as a possible outcome depending on the biopsy results. At the same time Maja was never given this fact with this much clarity during the time I had the chance to listen, as she asks doctors about it. Instead she was told not to worry. What bears the strongest significance for Heartisans is that the technological examinations have showed that Maja's condition is so bad that she probably would die in a matter of weeks, maybe days, if a mechanical help-heart was not put inside her chest. The threat of death was sufficient for the team to start taking action. There was no time to spare. Meanwhile, hope, regarded a pre-requisite for the success of the treatment, had to be kept alive.

This particular ethical dilemma is nothing of a novelty in clinical practice, and has been the subject of scrutiny in the literature on ethics in medicine. The obligation of medical professionals to provide full and honest information to a patient enables the patient to get involved in the treatment and in the decision-making process, and is often described as necessary for obtaining a proper informed consent. This is, in the literature on ethics in medicine, also called the "principle of respect for autonomy" (Beauchamp and Childress 2001: 63). However, in the reality of clinical practice, certain information is regarded as a threat to the sense of hope and safety, thus also threatening the success of the treatment. On the University of Washington School of Medicine's 'Ethics in Medicine' website, the following advice is given: "If the physician has some compelling reason to think that disclosure would create a real and predictable

harmful effect on the patient, it may be justified to withhold truthful information” (1998). This judgment of what is to be considered to be a compelling reason and real and predictable harm is made by a physician and is referred to as “therapeutic privilege”. Elsewhere it is called “justified strong paternalism” (Beauchamp and Childress 2001: 185, 186). As the Heartlands cases suggest, a medical specialist is regarded as the holder of the kind of knowledge and training adequate enough to make these kinds of judgments. In addition, in Heartlands culture, creation and maintenance of hope seems to be a number one priority and the key principle guiding the rationale of these judgments.

In sum, the overall criteria used in selection practices are quite ambiguous and vaguely formulated. They were not made explicit in national cardiac care guidelines or in any other official document in Heartlands. Instead, the criteria that were enacted in practice were derived from a more global level – the Criteria Committee of the New York Heart Association and the International Society for Heart and Lung Transplantation. Hence, the global macro-level criteria are enacted locally on the micro-level, where they were treated more as rule of thumb than as a required principle. The criteria that are summed up and listed below are not a reprint of any official document but have been observed as they were enacted by Heartisans during the selection rituals in Heartlands:

1. Threat of death – assessed life expectancy of a heart failure patient should be less than one year. In a word, the implantation of the mechanical help-heart requires the threat of death.
2. Age – the upper age mark says that patients older than 65 years should not be considered for heart transplant. However, the final decision is the job, license, and responsibility of doctors. So if a patient is considered in relatively good shape he or she might be accepted for heart transplant in spite of being a couple of years older than the age marker suggests. On the other hand, being younger than 65 cannot alone

guarantee a heart transplant to anyone. Other criteria must be met as well.

3. Last resort – all conventional treatments must be proven inadequate first before mechanical help-heart treatment is considered.
4. Stable family support – social circumstances and strong family support is seen as essential.
5. Communication – it is considered necessary for a patient to be able to communicate for successful transplant. In this way the understanding of a complex drug regimen and the compliance are assured.
6. Sobriety – use of tobacco should be reduced or eliminated and substance abuse (including alcohol) is considered a contraindication.
7. Sufficiently good general health – other diseases such as cancer, artery diseases, pulmonary tension, liver or kidney dysfunction, severe lung diseases, and even conditions like bad teeth are regarded as a threat to successful heart transplant treatment and must be ruled out or cured prior to heart transplant.

Selection is a set of practices carried out as a way of coping with the uncertainty and risk inherent in such treatments as implantation of a mechanical help-heart and heart transplantation. Standardization and regularization are used as prevention of the unexpected turns in this complex activity. At the same time expectations of what a mechanical help-heart patient should be like are expressed thus:

1. Sufficiently young yet dying
2. Not responding to conventional heart medicine
3. Having loyal friends and family who are ready to commit
4. Having no communication problems
5. Having no comprehension problems
6. Sober

7. Apart from his/her heart problems, in acceptable physical shape

This means that there are many others who never can fit within this frame – people whose age, stage of illness, responsiveness to conventional drugs and treatments, lack of support at home, communication or comprehension disabilities and/or other health problems prohibit them from implantation of a mechanical help-heart and/or heart transplantation. Those accepted are identifiable through these criteria, which become somewhat of a feature that is theirs only and that defines them as a group. They are special. Still, their uniqueness is also wrapped in an aura of gloom as it is born of one criterion overshadowing all other criteria – the approaching death.

DISCUSSION MEETINGS

Early one morning at the Department of Cardiothoracic and Vascular Surgery – a morning ritual called the ‘X-ray round’ was about to start. The ritual’s site is a dark, quite large room, equipped with two big cinema-like screens placed next to each other and two projectors hanging from the ceiling in the middle of the room. Heartisans call it the “thorax-demonstration room”. Two beams of light from both projectors stretched and expanded until they embraced the screens completely, displaying a variety of moving and still pictures: X-ray, angiography, CT-scan, ultra-sound. Three rows of seats, arranged as in a movie theatre, were facing the screens. About half of the seats were occupied by primarily surgeons and also by few anesthesiologists, all of whom were discussing and consulting each other about the cases – the patients – that are being put on display in the form of numbers, images, and diagrams. On the left side of the room was a desk and two monitors, behind one of which a radiologist was in charge of the playback of the cases recorded with various technology – something of a Heartlands very own Video Jockey who also functioned as a chairman of this particular congregation. In the midst of a hot discussion regarding the case featured on the screen

someone posed a question, “Well, then we are forced to take this up with the cardiologists... who will speak with the cardiologists?”. The whole group responded with loud laughter, obviously amused by this question, while at the same time avoiding taking on this task, as if it was somehow repugnant. “Who will act as a cardiologist?”, asked the chairman again, causing everyone to burst into even louder laughter. On the screens, an X-ray image of lungs with metastasized cancer was displayed.

The doctors gather in this room to discuss the prognosis of the patients. This practice is referred to as “X-ray round”. The general purpose of this practice is pursuit of consensus and reduction of signs of indeterminacy regarding the treatment of each patient that is being discussed. It is here that the patient’s imminent future is envisaged, based on the images displayed on these two screens. The patients discussed here are all candidates for surgery, i.e. persons that conventional cardiology alone could not save. This room is used every day at 08.00 to discuss:

- I. Patients at the Department of Cardiology who seem not to respond to conventional treatment
- II. Patients at the Thoracic ward and at the Thoracic Intensive Care Unit (TICU). The purpose of discussing these patients is to prepare and arrange for the planned operations and also to follow up the ones that are already carried out.
- III. Moreover, this room is used for extra meetings where doctors discuss various patients requiring emergency surgery.

There are two other formal meetings held weekly, where HeartMate-and/or transplantation patients are discussed exclusively – the Transplantation-round and the HeartMate-meeting. These are usually held elsewhere⁹⁷ unless the imminent surgical intervention requires a

⁹⁷ The Transplantation-round is usually held every Tuesday at 11:00 in a room called “The Pace” (*Pacen*). HeartMate-meeting is usually held every Thursday at 16:00 in a room called “The Pump” (*Pumpen*). Other rooms where similar kinds

discussion that is perceived as dependant on the high-tech equipment of the thorax-demonstration room. During the Transplantation-rounds and HeartMate-meetings the group is not composed only of surgeons, anesthesiologists, and radiologists, which is most common during X-ray rounds; it also includes cardiologists, perfusionists, nurses, a physiotherapist, a nutritionist, and a hospital social worker (a counselor)⁹⁸. The patient does not attend these meetings in person. Nevertheless, he or she is present in the form of images, numbers, diagrams, stories told, and subject matters discussed. This is clearly a good example of multi-professional gatherings, where each of the attendants is expected to contribute his or her expertise to the team effort. There is a general sense of mutual respect across the borders of various medical/clinical/technological/ areas of expertise that permeates these meetings. Yet, sometimes conflicts take place, professionals disagree, and resort to bickering and power struggles. The jokes at the expense of the other professions are quite common although often rather harmless – they seem to help strengthen the sense of belonging to a certain group of experts and thus provide the indispensable self-esteem boost in a job where decisions to be made often mean the difference between life and death.

On another occasion, during an emergency HeartMate-meeting held in the Thorax-Demonstration Room instead of the usual Pumpen locale, as the doctors wanted to utilize biotechnological images during the discussion, an end-stage heart failure patient, Bengt-Erik, was discussed regarding a HeartMate-implantation. The main question was whether he, considering his present condition, should be treated with a mechanical help-heart or not, and if so, when. Participants were perfusionist Roffe, radiologist Orvar, anesthesiologist Emil, cardiologists Patricia, Jakob, and Kent, Physiotherapist Leah, Nurse Johan... but thus far there were no

of meetings are held are named "The Pulse" (*Puls*en), "The Chamber" (*Kammaren*) and "The Atrium" (*Förmaket*).

⁹⁸ During transplantation rounds also doctor's secretaries are present as they play important roles in coordination between this hospital and the hospital where transplantation will be carried out.

surgeons in the room. The meeting started without them. Doctor Patricia read the case history aloud, covering everything from implantation of the mechanical aortic valve in 1996, to implantation of a CRT ICD⁹⁹ in 2006, and further to a sudden deterioration last hospitalization four times for conventional cardiological treatment. Then she gave an account of his current worsening condition, adding that he is now being evaluated for heart transplantation. Thereafter the discussion, accompanied by some ultra-sound images of Bengt-Erik's enlarged left ventricle on the big screen, revolved around: a) physiological details of the size and the shape of his left ventricle (100 mm) and the shape of the mitralis and right atrium, b) exercise test results, c) the mystery of how Bengt-Erik managed to get by [*han bar väl halkat sig fram*] in spite of being "heavily, objectively, sick", i.e. about inconsistency of the patient's "real" condition with the symptoms that he was showing – or rather was not showing, d) comparison between examinations performed at X hospital and those made in Heartlands, e) other diseases, f) the function of other organs (he had a slightly weak liver but was "otherwise healthy"), g) his clinical status and inotropic treatment, h) comparison with other end-stage heart failure patients treated with a mechanical help-heart, and i) initiated heart transplant evaluation. "Do we need more?" Doctor Emil asked. Patricia suggested, "Coronary angiography?". "No, we might want to go easy on the kidneys!" someone responded. After all the facts were taken into account it was time to discuss practicalities. TICU needs to regroup and prepare for taking over the patient from the Heart Failure Ward. Emil, representing TICU, explained that they usually accept new patients on Tuesdays and Wednesdays: "They should preferably come to us [TICU] two days prior to operation". Apparently, there is such a thing as "good timing" for transfer of the patient before surgery. A CT scan of the stomach is ordered by Patricia for malignity.

⁹⁹ Cardiac Resynchronization Therapy Implantable Cardioverter Defibrillator – a device used to help treat heart failure by making the different sides of the heart muscle contract synchronously and improving the overall function of the heart.

Doctor Karl, professor in thoracic surgery and most experienced among the HeartMate-team¹⁰⁰ members, entered the room. After being comprehensively updated, Karl pointed out that they must count on reoperation and requests a CT thorax on the patient to see how the heart is located as it can be rather difficult to saw up if the heart is pressed against the sternum. He also said that they've performed operations similar to this one before but that one loses the thread a bit in-between cases. Then Karl also noted that they must gather their forces so that they can deal with this...maybe at the end of the week. Jakob and Patricia raised their voice in unison saying that they want it to happen next week because they don't know if they can keep him alive much longer. Karl said: "End of next week, most likely". The meeting was closed. After the meeting Patricia went to the ward to inform Bengt-Erik about the mechanical help-heart.

In sum, the purpose of discussion meetings seems quite clear; they provide doctors with opportunities to share their experience with one another in order to evaluate the situation thoroughly, aiming for consensus about the most suitable treatment plan for the patient. Meetings work as a forum where doctors can build the shared understanding about the case together by contributing their particular expertise from different areas of biomedicine. Furthermore, the consensus itself is an indispensable feature in allocating the burden of individual accountability for the planned treatment. Discussion meetings also bring individuals together and put them into action as a group (Durkheim 1915: 348). While discussion meetings assembling only cardiologists¹⁰¹ or only professionals with access to the operating room (surgeons and anesthesiologists) help strengthen their sense of belonging to their group by routinized joking at the expense of other

¹⁰⁰ HeartMate-team refers to all the professionals assembled in a treatment of mechanical help-heart patients. This group consists of cardiologists, surgeons, nurses, physiotherapists, dietitians, and a hospital social worker and holds weekly HeartMate meetings where the treatment of these particular patients are discussed.

¹⁰¹ As a main group of physicians, that is. In addition, physiotherapists, nutritionists etc are often likely to be attending some of these meetings.

groups¹⁰² the multi-professional gatherings, such as this one, provide relief from whatever tensions such joking might rouse and create the general sense of what Durkheim calls *collective effervescence* across professional boundaries (Ibid). Ultimately, the complex sense of shared understanding, meaningful practice, and professional belonging is the very basis of creation and maintenance of hope – this is where all the factors that may contribute to creation of hope are singled out, brought together and organized into a plan of action of which the ultimate aim is to establish hope as a potentiality that can be actualized. Patients never attend these practices. Their presence is reduced to that of technological images displayed on the big screen, journal notes, and information reported. The information they receive about what has been said during the discussion meetings consists of a brief summary.

SUMMARY

Rites of separation consist of two parallel and intertwined processes: i) sick persons are socialized into Heartisan culture, becoming in the process Heartisans themselves; and ii) the foundation of hope is forged through the qualitative effect of stringently routinized – ritualized – practices and use of modern high technology.

Throughout the whole process of separation patients are carefully selected for the most suitable treatment, and are through this process also gradually initiated into a new kind of patienthood. They are instructed about what counts as relevant and what does not, what they should hope for and what is beyond hope, what is the proper way to tell stories and do things, who asks what kind of questions and who gives what kind of response, who is in charge of a situation and who is not. Thus, they are socialized into Heartlands society, becoming Heartisans in their new role as HeartMate-patients. Only after being integrated into a Heartisan culture is a person with a sick heart considered ready for the next phase in the treatment. By being provided a place in Heartlands as Heartisans, patients are also

¹⁰² Symbolical accentuation of inter-group differences.

provided with a sense of belonging in the midst of the abyss of their disrupted lives. Through these rituals, while the sick persons leave their normal lives behind, their heart problems are given particular social and cultural recognition and their life with heart failure is made into a collective concern. To be more precise, heart failure is, through biomedical healing rituals, brought out from the solitude of private experience into the public light of community, where it is formally shared with other people and transformed into an object for collective attention, concern, and effort. Furthermore, the sheer enactment of sharing is what makes the pointless suffering into something meaningful – something worth sharing. Hence, the individual suffering is distributed. Ultimately, as their intimate individual problems are through these rituals socially and culturally recognized and turned into a collective concern, the recognition surfaces as something that both enables and calls for hope.

Strict ordering of practices into standardized and formal procedures helps to trim down the effect of indeterminacy inherent in mechanical help-heart treatment. In addition, the all-embracing use and reliance on medical technology, as a way of extending the power of medical professionals, helps create the sense and image of potency in a seemingly impotent situation. In particular, with utilization of recent developments of various pump systems and treatment concepts, “[all] kinds of severe HF [heart failure] have a treatment option regardless of cause” (Granfeldt 2010: 14). New technology serves, thus, as a proof of medical power where nothing else works. The seemingly hopeless situation of end-stage heart failure patients is in a strictly disciplined high-tech environment turned into something that still might provide some room for tiny glimpses of hope. With this foundation laid down, the time is right to get the treatment started.

CHAPTER FIVE – TRANSITION

Transition is the second stage of the mechanical help-heart treatment during which a successfully separated patient is actually being treated. The completion of rites of separation is marked by information rituals through which the sick person is provided with information about his or her situation and about the available options. At the same time, informing also marks the start of something new – a launch into the unknown – a hallmark of liminal ambiguity. This mid-stage of the mechanical help-heart treatment consists of three sets of rituals:

1. Preparation

- a. Information
- b. Optimization
- c. Organization

2. Operation

3. Post-operative care

- a. Awakening
- b. The ward

First, the patient is subjected to standard preparations before the operation. After this a mechanical help-heart is surgically implanted in the patient's body, and the surgery is followed by post-operative care and treatment. With the beginning of this second phase the process of the patient's separation from his or her former self is completed. However, the goal of transition into his or her new self has not yet been reached. Thus the patient is caught between two worlds into a time and space marked by an intensified ambiguity – an ambiguity that is instigated by the clinical practice chronicle that connects the first set of practices (separation) with the second one (liminality):

1. Once diagnosed with end-stage heart failure, the patient is neither healthy nor merely sick any more but is, instead, recognized as dying.
2. Once admitted to a hospital, the patient is no longer partaking in the usual course of his or her daily life with family, friends,

peers, and colleagues, nor is he/she engaging in his/her usual daily tasks, work assignments, hobbies, or habits.

3. Once socialized into a mechanical help-heart patient, the person is no longer merely a person with ill heart.
4. Once acted upon through the routinized steps of mechanical help-heart treatment, the person is no longer independent – his or her survival is now dependent on the success of this particular medical treatment, i.e. on the level of sophistication of professional skill and medical technology.

Consequently, due to the processual character of the treatment, the patient is not immediately transformed into his or her new self. The patient is not yet ‘saved’, not yet back in the usual course of daily life with an improved – stronger – or completely new heart, not yet his/her own, not yet independent. This particular state is characterized by the ambiguity and indeterminacy of being caught between conceptual boundaries of hope/despair, life/death, body/machine, well/not well, non-patient/patient. Persons treated with the mechanical help-heart treatment are liminal mainly in a sense that they are caught like a pendulum in a motion between the life they have lost and the life they are about to gain, neither here nor there. They are interim persons in-between two ordinary structures, between two personhoods – the liminals.

Hope, instigated with diagnosis and selection, remains the main property of mechanical help-heart treatment throughout the entire stage of transition. This reveals, oddly enough, the substantially qualitative nature of an otherwise utterly quantitative practice in which social, cultural, and emotional aspects of illness are systematically downplayed in favor of quantifiable facts. All practices that together compose the practices of transition have one thing in common – they are all aiming for hope, regardless of what their main, i.e. instrumental, objective might be.

I PREPARATION

What I refer to as preparation consists of three interconnected sets of practices: i) information, ii) optimization, and iii) organization. First, after being selected for implantation, the patient is informed about the decision that has been made and also about how further treatment is planned. Thereafter, various preparations for planned treatment – further examinations and optimizing treatments – are instigated. Finally, people, technology, and space central to the treatment are prepared for the task. Preparation is the first group of practices in the patient's transition through liminality of treatment and mechanical help-heart patienthood.

INFORMATION

“Emotions are but a result of physiological processes”, argued Nurse Johan, concluding with conviction, “they are no more than an expression of hormonal imbalance”. With reference to the body of knowledge based on biomedical research, Johan knew for a fact that emotions and emotional states are connected to increased activity of various hormones and that an artificial manipulation of these hormones also can have an impact on the character of emotions. This empirically observable relation between hormones and emotions led him to conclude that emotions are caused by physiological processes through which the normal hormonal composition of the body is put out of balance.

Some medical doctors are particularly skilled at balancing these hormones by prescribing the right pharmaceuticals and also by necessitating the appropriate life style changes. This is how they bring the bodily chemicals – hormones – into desired equilibrium. Clinical research and experience have demonstrated that hormonal activity and emotions are linked and that the manipulation of former alters the quality of the latter. From this observation, Nurse Johan inferred that emotions are “no more” than an expression of hormonal activity.

Hence, lived emotions are conceptualized as an effect of measurable physiological processes. This means that these physiological processes are the exclusive origin and cause of all emotions.

With this rhetoric, felt emotions are reduced to a swirl of hormones. This puts the two connected modes, one measurable and other perceptible, in order of precedence: the arousal of emotions is caused by the hormonal activity. The meanings that people usually attribute to their feelings are, thus, ascribed an inferior and semi-real status in relation to hormones. What's more, Johan further infers that, provided that emotions are a result of physiological processes, we can and should learn how to deal with them using good sense and force of reason.

Regardless of whether Johan really wanted to emphasize the physiological processes as explanation of not yet conceptualized emotions-as-bodily-sensations, or if he wasn't at all aiming to establish the causal relation between the two but just to point out that the emotions and physiological processes occur simultaneously, his conviction echoed one of the main principles of medical science – to seek for answers in nature, i.e. in this case in ongoing physiological processes within human body. This way, for Johan, things made sense. Emotions are no more than the composition and dynamics of bodily hormones. To assume that there might be something else to emotions would perhaps be far too vague, ambiguous, and unscientific for a Heartisan – not enough evidence-based. This statement reveals two things, namely a particular take on knowledge (as evidence-based) and particular view of human emotions (as physiological). The outlines and content of what counts as 'nature' and 'knowledge' are here clearly defined. Curious about what made him so certain about this and how firm his belief was, I asked: "Can you know for sure that it is never the other way around – can there be occasions when experienced emotions give spur to these physiological processes?". I wanted to see whether Johan could imagine the idea that there can be something between the experienced event (an encounter, an episode, or a phenomenon) and the change in

composition, concentration and color of a person's hormonal cocktail; some dimension of being human that is not readily reduced to physiology; something that determines why certain events in our lives affect us in certain ways. Johan dismissed this idea as downright silly.

I don't know whether all or even significantly many Heartisans would make the same inference as Johan. Neither do I know exactly how loyal they all really are to physiological explanatory models, or how open they are to other perspectives. Nevertheless, what Johan's argument does is that it captures the general sentiment and attitudes towards human body, health and illness, wellbeing and life-crisis, emotions, and reason in Heartlands. This sentiment is then transferred to patients in their encounters with medical professionals.

Heartisans inform

The patient receives information primarily from doctors and nurses¹⁰³: a) directly through formalized information talks, b) spontaneously during other tasks being performed, and c) in the form of brochures and manuals. The very first time patients are told that they are about to die if they don't get a mechanical help-heart is one of such formalized information talks. This particular information is usually also the point when preparation practices begin. It is not to be confused with the first time that the patient has been informed about his or her health status and prognosis in general. Patients are informed continuously right from the first time they encounter medical and/or health care professionals. What makes this particular information special is that they make a particular kind of situation (approaching death) and particular kind of solution (mechanical help-heart treatment) known to the patient. The nature of this information is twofold – a bad-news-good-news kind of sentiment. The bad news is “you're dying”, and the good news is “there's hope!”. The explicit

¹⁰³ And to some extent also from other health-care professionals such as physiotherapists, dieticians, hospital social workers, etc.

form and content of the information provided highlights the good news part whereas the bad news part is not emphasized concretely.

After this first initial information talk, information continues and the patient is, each time he or she meets a doctor or a nurse, repeatedly updated about his or her current status and the planned treatment. These patients meet their cardiologist on several occasions before the operation, during which they are informed about the treatment. They also meet the surgeon, the anesthesiologist, the perfusionist and the physiotherapist for more information. These talks emphasize details of the procedure, including the stakes, the expected outcome, predictions, technical details about the mechanical help-heart, physiological details, and benefits. They also emphasize the practical details of living with the mechanical help-heart, of pre- and post-operative challenges, of what kind of effort the procedure requires from the patient and his or her relatives¹⁰⁴. Furthermore, information is also given by ‘veteran’ patients themselves – survivors confirming the success of this particular kind of treatment. And finally, patients and their relatives also read the booklets and brochures from companies manufacturing mechanical help-hearts¹⁰⁵. After the emergency HeartMate-meeting¹⁰⁶, Doctor Patricia brought the news to Bengt-Erik: “We’ve concluded that it’s going to be one of those pumps... a HeartMate[®]”, she said, “It’s planned for next week... if you want to?”. “I don’t have much choice” Bengt-Erik answered. “No, you don’t”, she confirmed, “but you’ll get loads of

¹⁰⁴ Although it happens that patients ask questions about the treatment and about the mechanical help-heart on the occasions they get to meet a doctor, it is quite uncommon. Most often they just listen to whatever doctors are talking about and answer the doctor’s questions dutifully and concisely. In between the encounters with doctors they have quite a lot of time at their disposal for pondering their situation in solitude. ‘How could this happen to me?’, ‘How am I gonna deal with this and that?’ and so on – then, when the doctor finally arrives the patient thinks: “Hmm, there was something else I was wondering about... mmm, but I can’t remember it right now...” (Eina, excerpted from the Fieldnotes).

¹⁰⁵ See pp 233-239.

¹⁰⁶ See pp 215-217.

information. I'm sure you have a lot of questions but it will all be clearer in due course".

Convinced that Bengt-Erik would die if left untreated, doctors never presented this to him as an option. He himself saw no other options than to accept the treatment, thus acknowledging the limits of his action-space. While the bad news part – “you’re dying” – was not explicitly stated, it was nonetheless acknowledged as a non-option. Instead, the talk focused on the good news, avoiding the bad news part completely. The mere existence of this particular kind of good news¹⁰⁷ confirmed the imminence of death in a way that made an explicit emphasis superfluous. Meanwhile, death was scrupulously avoided as an overt subject of the information talks.

During my time in Heartlands, doctors, nurses, patients and patients’ relatives readily praised his/her will to fight, strength to endure suffering and pain, and determination not to back down before the threat of death. Such virtues were usually honored as something good – a personal quality that is desirable and highly valued. The example of information talk displayed above shows how a patient’s actorship is reduced to mere compliance. In fact, to fight, or not to give up, becomes equivalent with accepting the biomedical salvation that is offered as the only option when death is the alternative. Thus hope becomes a virtue. Bengt-Erik showed that he was aware of this by saying that he had no choice. The doctor nodded, confirming it.

Cornered by the approaching death the patient offered no resistance to the experts’ advice to get “one of those pumps”. The pump was his only hope – the only way out of the cul-de-sac that his end-stage heart failure has gotten him into. Was it his fear of the finitude of death that made this an easy choice for Bengt-Erik? Or is it but a natural posture of all things alive to resist the absence of life? Be that as it may, the following episode from the Heartlands suggests that this posture is certainly cultural and highly normative.

¹⁰⁷ The nature of this kind of good news is that it is a last biomedical option available.

During one of the morning work rounds a patient insisted on being released from the hospital. He showed no signs of fear in spite of a clinically estimated high risk of dying without treatment. The doctor tried to convince the patient by saying, “What is most important to you: your health or to get home? Now you’ve been brought by the ambulance the whole way down here ... and it wasn’t without reason, but because you need the care that we can give you here. Honestly, I believe [*jag tror*] that you are going to die if we send you home”. The patient persisted: “Yeah, well, I don’t believe so [*jag tror inte det*]”. “It’s not a matter of belief [*Det är ingen trosfråga!*]”, the doctor concluded authoritatively, “I’ve been working with this for twenty years now so I know that it so”.

This time, instead of being avoided as an overt subject of discussion, death was explicitly evoked by doctor, “... you are going to die!”. By referring to the imminent threat of death, he acted upon the patient’s lack of fear by assuring him that he will die if he leaves the hospital untreated. Furthermore, the doctor assumed that the patient’s lack of fear was caused by his lack of understanding of the severity of the situation – so he took on the responsibility of enlightening him. The lack of fear was thus being managed through a discursive strategy where the doctor regulated the patient’s level of fear by informing him about the inevitable consequences that it may be leading him to – death. Grounded in the expert knowledge of a doctor, this strategy finally caused the patient to change his mind and stay in the hospital to be treated. Thus, the hope has been enacted through a death-without-the-treatment discursive strategy based on the assumption that staying in the hospital and undergoing the treatment is the patient’s only hope for survival. So, in order for fear to be instilled and felt, the reality of danger must be ascertained. The patient in this example wasn’t lacking fear itself but rather something to fear. Only after the object of his fear was established – death-without-the-treatment – could the hope be presented and proposed. Rather than being individual, hope is here enacted as a social phenomenon, existing in interaction between a doctor and a patient, suspended in

Heartisans' cultural web of significance as the normative alternative to death.

Ironically, the medical profession would be completely unnecessary if doctors could succeed in defeating diseases and, ultimately, death: "The paradoxical role of medicine consists, above all, in neutralizing [doctors and patients.] ... medicine attains its aim in a gradual neutralization of itself. The condition of its truth is the necessity that blurs its outlines", (Foucault 2006[1963]: 8-9). Still, turning down the gift of hope in face of hopelessness before certain death would amongst the Heartisans be considered at least as extremely odd. It would, no doubt, be a breach of fundamental cultural ethos in a place where saving lives is more than just a *modus operandi* – it is a condition of its truth.

The gift of hope in the case above was more than just an act of benevolence – it was also contractual. The sentiment of the doctor's attempt to enlighten the patient had left the patient with two options: i) accept the gift – stay and live; or ii) reject the gift – leave and die. As the episode unfolded the patient was prompted to discriminate between these options regarding the value of the importance that he associated with them. Then the doctor reminded him of the effort that has been invested in him by the medical and health care system (as a part of the Swedish welfare services) as he has been "brought by the ambulance the whole way" from one hospital to another, including the attention of medical professionals from two different hospitals. This reminder of the investment that has been made in the patient was deployed as a contract of reciprocity. According to the three rules of reciprocity, including the obligation to give, the obligation to receive, and the obligation to repay (Mauss 1997[1923-24]), the patient was expected to redeem the gift (hope valued as investment made). It was not viewed as an equivalent repayment – as reciprocal social exchange is based on the rules of moral economy rather than those of market economy (Andaya 2009) – but as a token of esteem in the form of compliance. This calls for morality as a standard for the right choice for a patient to make in the light of what

he was given. Hence, a trade of compliance for hope is offered – the reciprocity of interests (Perry 1909). Thus, morality of hope was established at the very core of this doctor-patient interaction.

As death is treated as a non-option the patient is encouraged to invest all of his trust in the knowledge of medical experts and all of his hope in “one of those pumps” – not necessarily so much due to its excellence as such, but perhaps more due to its being the only option available. Furthermore, to give up in spite of the efforts that have been invested in the patient would be regarded as downright rude and would render the patient unworthy of the treatment¹⁰⁸.

Survivor-patients inform

A meeting was arranged by Heartisans. Rune, a former heart transplantation patient, was called to inform Bengt-Erik, a patient facing mechanical help-heart implantation, about his experience of heart transplantation treatment. Rune was a neat, well-dressed man. He had received a new heart a couple of years ago and seemed now to be in exceptionally good shape. Cecilia, Bengt-Erik’s wife, was also present. They gathered in the patient’s room at the heart failure ward. Rune took the lead and chose the theme of the story he was telling. It was about how smoothly everything went for him and how his life was of high quality now after the transplantation. Bengt-Erik and Cecilia asked some questions about the practical details of transplantation¹⁰⁹. However, the emotional experience and ways of coping with losing one’s own heart and receiving someone else’s were not discussed. Neither was the risk of dying. On several occasions the conversation seemed to be headed in that direction, and at times they touched upon these sensitive issues, emotions, thoughts, and existential topics. Yet, every time, it also stopped there. Although it was recognized in passing as important, it was merely mentioned and

¹⁰⁸ For more examples see the ‘Compliance’ section (pp 241).

¹⁰⁹ Waiting, preparations, logistics, how to get to the hospital when the time comes – by train, car, bus, ambulance, helicopter, or airplane – what they should think of, how long the recovery will take, and how things are done regarding medication after surgery.

then instantly dropped. The core purpose of this conversation seemed to be providing hope, and highlighting the emotional and existential hardships would counteract this. One of the things in particular that were said during this meeting had stuck in my mind:

Rune: Most of the [transplant patients] that I have met have made it alright and that's how it is, they [the doctors] are getting better and better, more skilled... so that's just the way it is... it's progress.... and there are also good medications ... yeah, it's really fantastic how they [doctors] can do this.

(Excerpted and transcribed from audio recording,
translated by author)

More than two months after this encounter, during one of our many talks, Bengt-Erik recalled his encounter with Rune and said to me with a sigh: “I hope I’ll be as vigorous as Rune”.

Arranging encounters, between survivor-patients and the novices, is a well-established part of this treatment. The patient who does the informing is not just any patient with experience of this kind of treatment, but is carefully handpicked by doctors. For instance, Moa, a young woman in her thirties who was known among Heartisans for her unfortunate suffering during her six months with a mechanical help-heart, with no signs of improvement or possibility to leave the hospital, was not chosen to be Bengt-Erik’s informer, nor were any of the other patients who have had painful experiences with their mechanical help-hearts. Of course, and for an obvious reason, neither were those who have died during their time with HeartMate®, or those who died on the operation table¹¹⁰.

¹¹⁰ Some of these less successful cases were often brought up during coffee and lunch breaks in Heartlands where they are told and retold among the

Doctors describe this practice of informing as a way for a new mechanical help-heart patient to get some answers for his or her questions. Patients and their relatives seem to share this view about this practice. Still, the scope and the character of answers thus acquired are shaped by doctors' choice of a suitable informer¹¹¹. There is a certain type of answers that is generally considered suitable. First, by sharing their experience of overcoming various hardships inherent in such tough treatments, survivor-patients provide practical tips and strategies that can be quite valuable for the novice. Thus, they create and offer to the novice the sense of safety and empowerment. Second, by merely presenting themselves as examples of the success of this particular treatment, the survivors embody the triumph of biomedicine and biomedical technology over disease and death and thus provide glimpses of what a novice's future might be like. Thus, they create and provide hope. Third, the fact that the informer is sharing his experience with others at the request of the same doctors who once gave him/her a gift of new life can also be viewed as a part of the moral economy of hope surrounding these practices. By passing on hope which he once was given, Rune acted in accordance with the moral obligations of reciprocity.

It appears to be widely held in Heartlands that safety cannot be achieved through stories of uncertainty, failure, and helplessness, nor can hope be achieved through stories of hopelessness, death, and suffering. To even mention such themes in front of a novice patient would be something of a taboo. Instead, only real success stories portraying the victory of dedication, determination, the will to fight, skilled medical professionals, and high technology are considered a proper way of providing confidence and hope. These stories provide hope, which was quite clear in Bengt-Erik's sigh: "I hope I'll be as

Heartisans. Under no circumstances, however, were they ever told to mechanical help-heart patients.

¹¹¹ During the conversation Rune reveals that this was not the first time he is doing the 'informing'. He has done it a couple of times before. This suggests that Rune has been ascribed the stature of a suitable informer and has been utilized for these purposes repeatedly.

vigorous as Rune⁹. In spite of the fact that Rune never had a mechanical help-heart, he was chosen to be Bengt-Erik's informer. One criterion that outweighed all others was the fact that Rune was, and still is, doing exceptionally well. He embodies a proper example of a survivor and is thus able to generate the valuable sense of safety and hope.

The dark sides of these treatments are almost never mentioned to novice patients by anyone in Heartlands. Should it occur, however, it was always rhetorically outweighed by all the positive things that are said about it, as if to portray it as something that should not be questioned¹¹². Rather than diminishing their value, occasional mention of practical difficulties and challenges brought with this treatment glorify the triumph of biomedicine, technology, and medical professionals in a fight against disease and death. Furthermore, it also helps the patient realize how dependant he or she is on the medical professionals, emphasizing once again the importance of a patient's compliance.

Manufacturers inform

Already in the first chapter of this thesis I mentioned the role that the Medical Industrial Complex (MIC) plays in creating an image of these treatments. New medical technology is praised by various manufacturers of different mechanical help-heart systems. The praise comes as commercial/informative material in form of reports, brochures, websites and DVD-films featuring success stories about and/or interviews with survivor-patients. Through these stories, new medical technology is portrayed as a property of a future that is continuously being colonized by experimental medical science and put into evidence-based medical practice¹¹³. At the same time as they

¹¹² Much like the ways in which progress and new medical technology are portrayed in the media and in the popular culture. This was already discussed earlier in 'Technology of hope' section (pp 26).

¹¹³ The same stories are also reflected in the media coverage of medical innovativeness, especially when it comes to mechanical help-heart technology (see pp 26-29).

are accounts of the past and the present – a real-time look in the rearview mirror of the current state of affairs – the stories of success carry, by the sheer suggestive power of inductive reasoning, hope, and promises of rescue that lie in the future. In other words, based on success stories from the past they tell the future for the dying.

“Heart Hope” is an organization founded by Thoratec Corporation, the manufacturer of the HeartMate® Left Ventricular Assist Device. On their website¹¹⁴ there is a topic called “Recent Stories”, featuring over a hundred exciting success stories. Note that these are only the recent ones. Here, various news articles depicting the advance of new technology are collected. Most of them feature medical doctors who comment on the topic. For instance, in one of the recent articles, a Texas doctor Dan Meyer says:

While this [implantation of a mechanical help-heart] does involve a major surgical procedure, most patients are able to go home 10 to 14 days after surgery and engage in normal activity, including driving and travelling (Heart Hope 2010).

To have normal activities such as driving and travelling to look forward to sounds promising indeed – and this is the whole point of the Heart Hope as a network. The following is an excerpt taken from the Heart Hope website:


What is Heart Hope®? Heart Hope is a network of healthcare professionals dedicated to advancing the treatment of heart failure. Its mission is to communicate a message of hope and empowerment to heart failure patients, families, and caregivers. We invite you to explore this website to discover how every day can be a new beginning for you or someone you love who suffers from heart failure (URL: <http://www.hearthope.com/index.asp>).

These medical professionals offer hope and empowerment and promise a new beginning for the dying. In addition to “Recent

¹¹⁴ URL: www.hearthope.com, date of access: May 16th 2011.

Stories” there is another topic, “Patient Testimonials”, featured on the website. Here, success stories of thirteen survivor-patients are offered in the form of a filmed interview which can be viewed directly. The survivor-patients featured in the interviews use language of devotion, awe, and conviction when sharing their experience. An older gentleman named Marvin says: "When you stop and think of

New Hope. New Life.



HeartMate II[®]
Left Ventricular Assist System

Proven Treatment for Advanced
Heart Failure Patients

Figure 21: The front-page of a brochure containing information about mechanical help-heart treatment. This brochure is made and distributed by the manufacturer. (Reprinted with permission from Thoratec Corporation)

how your life has changed... that is well worth the little bit of inconvenience". Another one named Dave says: "I have a good life right now and [my heart pump] keeps me there, keeps me going, keeps me happy". A young lady called Janna says: "If I were talking to somebody who was trying to make the decision whether or not to get a heart pump I would definitely say to go ahead and do it" (HeartHope 2011).

I requested and received a package from HeartHope of information material including one brochure and three DVDs. The brochure is entitled "New Hope. New Life" and each of the three DVDs offers a particular kind of information¹¹⁵. The industry of medical technology is an industry of hope. This calls to mind Foote's words, quoted earlier: "[It is a] multibillion dollar industry producing thousands of products ... The demand seems insatiable. We have come to expect a steady stream of new 'miracles'", (1992: 4)¹¹⁶.

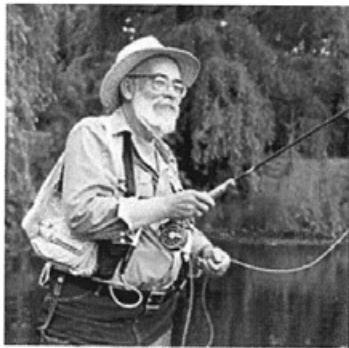
However, there is one particular form of information from the manufacturer that Heartisans give to the patient directly – patient manuals for their new mechanical help-hearts. In these manuals technical specifications and practical details of managing the technological equipment that comes with a mechanical help-heart are meticulously accounted for. On the front-page a survivor-patient is portrayed in a beautiful setting – fly-fishing on a riverbank, and obviously enjoying life.

The sentiment that is being communicated by the manufacturers – through websites, periodicals, brochures, and films – makes the web of significance where the local practices of implanting mechanical help-hearts are situated. Their promise of hope, empowerment, and

¹¹⁵ DVD I) "A Team Approach Top Mechanical Circulatory Support"; DVD II) "Living With HeartMate – Patients share their experiences of living with a ventricular assist device"; and DVD III) Ventricular Assist Device (VAD): A Treatment Choice for Heart Failure – A shared decision-making tool for patients, physicians, and implanting centres". This information kit is delivered free to anyone who is interested in getting it.

¹¹⁶ This sentiment is expressed in the Peter's enunciation quoted earlier (see PROLOGUE).

ultimately victory over heart disease is the vital force in creation of global cultures of hope. On the local level, in the hospitals such as Heartlands, these promises are distributed through formal practices of informing, i.e. rites of becoming where scientific and clinical expert doctors and nurses and also survivor-patients play crucial roles as narrators and/or living proof of biomedical and biotechnological success-stories, stories of triumph. Patients are guided by these stories into a new level of their heart failure patienthood – they are becoming mechanical help-heart patients.



Patienthandbok

Din vägledning till HeartMate II LVAS hjärtpump

Figure 22: This image is scanned from a front-page of a manual the patient receives from doctors. The text says: “Patient manual - your guide to HeartMate II LVAS heart pump” (my translation). This manual is a part of the information that is produced by the manufacturer and distributed by doctors to the patient (Reprinted with permission from Thoratec Corporation).

In sum, during the first part of the transition stage – the rites of preparation – the patient is informed. Not just any kind of information is considerable suitable, due to the shared idea that the purpose of this information is to provide a dying patient with hope.

Hence, stories about treatments gone wrong are regarded as discouraging and thus inappropriate. Generally, information is done through ritual practices of information and instructions and through stories of success. This success is put on display – embodied – in: 1) health care professionals (expert doctors representing medical science), 2) survivor-patients (victorious previews of patients' future selves exemplifying the effectiveness of medical science and technology), and 3) modern technology (the industry of biomedical technological innovation promising the miracles of hope, empowerment, and new beginnings). Hope is the main property of information rituals and can be identified in: a) discursive strategies for management and adjustment of a patient's emotions so as to align them to a common sense, or a good sense of Heartlands culture, b) the quality of doctor-patient relations that rest on the principles of reciprocity where the patient's acceptance and compliance with the recommended treatment is regarded as the only right choice, considering the scope of resources¹¹⁷ that are being invested in him or her, and c) distribution and usage of technological innovations that work as promises of the Medical Industrial Complex to treat or cure, and by doing so also provide hope to dying heart failure patients.

The explicit goal of information rituals is twofold. While providing enough information about practical details, preparations, logistics, and technical specifications, it also provides examples of the effectiveness of this treatment. The first goal (practical information) offers a sense of safety, power, and confidence to a novice patient. The second goal (display of success) serves as a preview of a novice patient's future self. Together, practical information and success stories make a proof of hope and a foundation for new hope. Everything takes place as if hope is the main property of information practices. How come hope is so highly valued in Heartlands? At least a part of the answer to this question is suggested by ethnographic data

¹¹⁷ Biomedical attention and knowledge, precious time of time strained Heartisans, a place in Heartlands, expensive treatments, medications and technology.

showing that the sense of hope is actively altered and managed as part of the preparations for planned treatment, revealing that the implicit goals of information rituals are management and adjustment of a patient's emotional disposition to a mode regarded as suitable for the planned treatment, and also obtaining his or her compliance.

OPTIMIZATION

In between information talks the patient is undergoing various examinations and is being medically optimized for the treatment, thus acknowledging his/her new "HeartMate-patient" identity as already accepted and embodied. Resources of personnel, technology, and medications are already activated. The patient's teeth are repaired, CT-scans, echocardiograms, and ultra-sounds are done. In the meantime, while all this is taking place, information practices continue. Optimization starts at the heart failure ward where the patient is given proper medication which will help "stimulate the heart" (*piska på hjärtat*) in order to stabilize his or her condition before the operation. After this the patient is transferred to TICU approximately two or three days before the operation. Here, the patient is "tubed up" (*slangad*) and further stabilized through various medications. At TICU the patient is monitored twenty-four hours a day. On the morning of the surgery the patient is "pre-medicated" (*premedicinerad*) with sedatives in order to remain calm going into the operation room. The explicit aim of optimization practices is to optimize the patient physiologically before the planned treatment. The final touch of premedication serves to prevent additional emotional pain when approaching the critical moment of operation. The implicit effect of optimization is that it already sets in motion the process for which information practices have prepared the patient, thus rendering its course unquestionable.

Upon the admission the patients are subjected to a particular institutional structure to which they must adjust. In fact, Heartlands as an institution is enclosing as all parts of daily activities are tightly scheduled into a standardized pattern of activities of which the

purpose is to serve the aims of the institution. First, on admission the Heartlands patients are put through certain procedures; they give their life histories and are weighed, they having rooms and bed numbers assigned to them, they have their clothes and possessions removed and stored, and are issued hospital gowns to wear. Moreover, facts about the patients which are considered private outside the hospital are disclosed and discussed within the Heartlands borders freely due to their ‘medical relevance’¹¹⁸.

Through the admission procedures and other initial practices the patient is structurally ordered under the principles of the institution and thus introduced to his or her place in it. The completion of admission procedures marks the definitive end of separation practices. At this point the patient has been repeatedly subjected to the structural program of the Heartlands institution. This diversity of practices is to a varying degree shaped and colored by a certain combination of the following properties: all patients are equal; they are all often referred to as a number (room or bed); together, they form a special collective within the Heartisan community; all their private property is stored away; they all wear similar clothes; they are expected to respect and follow the instructions; their personal style is disregarded; all patients are granted exemption from their duties and obligations outside the hospital; all patients are congratulated on displayed ability of endurance. Hence, the patients pass through the first institutional filter which prepares them for their complete transformation – the much longed-for status of living instead of the feared status of dying.

¹¹⁸ For instance, on one occasion a nurse discussed one patient’s history of alcohol abuse and his lying with his claim that he hadn’t been drinking for three years. It turned out that he, in fact, has been drinking throughout the past year, as much as one bottle of hard liquor a day. Another example is when a nurse reported to a doctor about a newly admitted patient who had been an amphetamine addict since the 90s, and who also was admitted for alcohol intoxication last year. Yet, in spite of these facts, he denied the substance abuse by referring to his job as a fitness instructor. A third one is when a doctor during the transplantation round called one patient a “failure” (sviktare), an “addict” and “suicidal”.

Compliance

During one of the lunch breaks Assistant Nurse Selma and Physiotherapist Lea told me a story about Alfred – a young man who has had a mechanical help-heart and who was later transplanted. Many stories were told about this young man by different people during my time in Heartlands. All of them were told among medical staff, shielded from the ears of patients. Selma described how hard it was to work with this patient because he was disobedient and did nothing as he was told to do. He didn't want to eat, didn't want to exercise. As a result, he was unable to attain the daily calorie intake numbers that were set as a goal for him. But Doctor Arvid didn't want to hear it, she said, so he would shout at Selma and say, "It's your job to make sure he eats and I want the cord [the percutaneous lead] to be bandaged and the patient put in a sitting position!". She took these reprimands seriously and always tried her best to make Alfred eat: "Alfred, please, please with sugar on top, please eat some", but, without success. Another problem was that Alfred wouldn't exercise either – all he wanted to do was to lie down and sleep, she said. Lea concurred with Selma. Things didn't go very well back then, she said, because she argued with Doctor Arvid about Alfred and about how much he should exercise. "I mean if he's not down for a train ride¹¹⁹ it is ridiculous to start pushing him", she said, adding that she and her fellow physiotherapists were sometimes actually pleased with how much Alfred exercised and would commend him: "Oh, well done, you are doing so well today, riding that bike up to sixty watts", and then Arvid would come and shout at Alfred "like a hurricane" for riding only sixty watts: "He should do at least a hundred!". This, according to Lea, was unrealistic. Such a reaction from a doctor caused the patient to lose all his confidence in physiotherapists; "But you said that it was good and that I was doing well!", Lea tried to mimic Alfred. Doctor Jakob had also gotten really upset, Lea said, "and when he gets upset it's really like too much". She felt as if the doctors have already decided how a patient is supposed to act, and

¹¹⁹ See pp 195.

said that it was almost as if they were saying: “If you don’t do as we tell you to than you’ll get no heart!”. “It was terrible”, she said, “because as soon as you don’t do as they want you to, you get to hear that “.

Instructing patients and expecting total obedience has a central place in the medical practice in Heartlands regarding all kind of heart patients. On one occasion, during the morning work round, Doctor Arvid explained to Fredrik, an alert-looking patient, that his heart’s pumping power is reduced and that they will give him medications that will make his heart better. At the same time Doctor Arvid instructed Fredrik about his action responsibility. “There are three things I want you to do”, he said, “first, you need to eat properly. You must increase your intake of proteins. You’ve lost about thirty kilos during just a few days and it’s important that you start building those muscles [Fredrik is literally skin and bone now and was around 90 kilos before]”. Furthermore, he told him that he must not drink more than one and a half liters of liquid per day if they were to succeed in getting the fluid out of his belly. Finally, he ordered him to start moving around more: “You have to fight! Think of this as a match!”, said Doctor Arvid and continued, “... you see, I myself train martial arts... each time you get on that mat and are about to meet your opponent you must think like a winner because that’s the only chance you have. Even the slightest hesitation reduces your chances immediately”. Once again, the will to fight, not to give up, was praised¹²⁰, and this time even prescribed to a patient in formal instruction. Doctor Arvid continued with a firm and dominant tone of voice, demanding “total honesty” from Fredrik: “If you’re the tiniest bit uncertain about fighting this match, I want you to speak up. I will accept that and we can put everything on the shelf ... there’s no use in investing anything if you’re not with us on this”.

The doctor mentioned the investment that was made in the patient and suggested that it was pointless treating the patient unless he does his part in it. This has two implications: a) the doctor

¹²⁰ See pp 227.

reminded the patient about his reciprocal bond with respect to what he's been given, and b) he also made it clear to the patient that if he does not comply with instructions, he will be denied further investments of expert knowledge, time, expensive medications, treatments, and technology. Any sign of resistance will be interpreted as a breach of the rules of reciprocity and will put him at odds with potent medical forces. He will be left on his own.

During my field work, compliance was praised as essential and obligatory. Lack of it was blamed for failure. Following instructions was considered as acting compliantly and therefore as being something good. But doing this while at the same time demonstrating the ability to endure pain and fear was regarded as the most prominent form of compliance. Display of such ability is commonly praised with “well done!” and “you’ve been so good!” or “you’re so brave!” while, for instance, occasional crying is described as just a brief moment of weakness (*en svacka*) in contrast to all the time of bravery and doing well. Meanwhile, any tendencies to complain more than usual, to show repeated signs of low-spiritedness and discouragement, or to cry recurrently were quickly labeled as depression, DAMP, etc.

In sum, during the second part of preparation (optimizing practices) the patient is optimized through medications of which the main purpose is to stabilize his/her overall physiological status for the planned surgical procedure. Because optimization practices are already underway while the patient is being informed, they also signal the unavoidability of this particular treatment – the only hope. Moreover, patients are socialized into the daily routines through admission procedures. Thus, they are being habituated, i.e. accustomed to and integrated into the Heartisan culture and, as a result, being programmed into ideal patients who are receptive to the treatment.

ORGANIZING

Troops assembly

The completion of diagnosis and selection announces a new situation in Heartlands – the emergence of a HeartMate-patient. Statistically, this occurs twice a year¹²¹. Each time, it causes a sudden disruption in the daily pace of the ward. The old order gets disturbed; a new one is put into practice. Although cooperation is not foreign to Heartisans, these new circumstances bring several wards and units with all their diversity of professions beyond a mere level of cooperation – they are quickly transformed and regrouped into one single team¹²².

Hope as social drama

People with end-stage heart failure are most often suffering from a variety of conditions that may be related to other medical domains than cardiology. This, together with the fact that the implantation of a mechanical help-heart is one of the toughest surgical procedures a human body can be exposed to, calls for additional close cooperation with doctors outside of the Heartlands. The branches of medicine most frequently involved in treatment of end-stage heart failure patients are infectious diseases, oncology, pulmonology, and nephrology. The teamwork also reaches beyond the boundaries of this particular hospital to other hospitals, countries, and even continents¹²³. In a matter of minutes, a local-level decision about the

¹²¹ During some calendar years Heartlands treats as many as five or six Heartmate-patients, whereas other years they may have none.

¹²² The treatment plan includes all three departments at the Heartlands, gathering staff including cardiologists, radiologists, anesthesiologists, surgeons, biomedical analysts, TICU specialist nurses and assistant nurses, CSU specialist nurses and assistant nurses, Heart Failure Ward nurses and assistant nurses, physiotherapists, dieticians, dentists, and counselors more intimately around the same patient.

¹²³ Various hospitals in Sweden cooperate on the issue of organ harvesting and organ distribution on a national level. There are other forums such as the Scandinavian Transplantation Society and the European Transplantation Society providing broader platforms for collaboration. The Heartisan surgeons and anaesthesiologists specializing in implantation of mechanical help-hearts turn to

implantation of a mechanical help-heart turns this local-level situation into a part of global-level practice.

The progress of technological development puts further pressure on Heartisans. The advances that are made between the cases of HeartMate-patients in Heartlands make the current routines old – they need to be updated. Many of the newly employed staff had not ever heard of the HeartMate®, or had only some vague idea of what it is¹²⁴. The entire Heartlands also changed with the arrival of a HeartMate-patient. During one of the weekly HeartMate-meetings – this particular one devoted completely to preparation for, and execution of, the implantation of a mechanical help-heart – Doctor Jakob, a chief cardiologist said to me: “Well, now things are happening... up to now you’ve got to see us in our sleep mode (*sömnaktiga*), but now we’re up and rollin’... now you’ve got something to study”.

Obviously, the arrival of a HeartMate-patient, once or twice a year, marks the entire Heartlands with a higher-than-usual level of attentiveness among the staff. The frequency of urgent situations increases; a brand new soundscape marks the Heartlands with odd kinds of alarms that suddenly echo throughout the corridors. The old daily routines are kept at bay, allowing for the new ones to take control of this unanticipated and demanding event. This is not to say that staff is not prepared for this kind of treatment – it is rather to say that it seems as if it’s in the nature of technological progress that no clinical center can ever be prepared enough for this kind of treatment. In Heartlands there are guidelines for how these situations are to be dealt with – the proper way of conduct. These formalized guiding

the manufacturers and distributors of these devices in the USA for help and assistance; a small but significant part of their surgical training is in fact done in the USA at some of the world’s most famous surgical centers which, in turn, also work very closely with the mechanical help-heart manufacturers and distributors.

¹²⁴ A surprising number of nurses, nursing assistants, and even apprentice doctors have on several occasions asked me about the way mechanical help-hearts work.

principles are quickly adhered to, as the new set of routines needs to be observed with total obedience by everyone involved. First, an emergency education program is organized to instruct the novice nurses and assistant nurses, and also to remind the experienced ones, of how the treatment and care of a HeartMate-patient is properly done. The teachers are perfusionists – the ones with the specific technical knowledge of the mechanical help-heart. Second, a one-day course on mechanical circulatory support systems was held for novice doctors in Heartlands during this period. A nurse at the Heart Failure Ward once said: “We try to arrange courses in how these patients and this particular technology is properly handled each time we have a mechanical help-heart patient. We’ve also tried to have these courses frequently, regardless of whether we are taking care of such patients for the moment or not... but it didn’t work out”. Third, the entire team that is directly involved in the treatment of a HeartMate-patient, including the chief doctors, arranges meetings more frequently than ever before to discuss the situation at hand. Besides the regular rounds and weekly meetings, new – extraordinary – gatherings are scheduled continuously during all stages of treatment. During these meetings doctors share their views with one another while evaluating the situation. They also review previous cases together and fill in the gaps in each other’s memories. The explicit goal is consensus.

Besides formal guiding principles, other, less formalized, routines are observed by medical staff. First, nurses, assistant nurses, and novice doctors search sporadically through official policies and guidelines for information. Second, they also look for answers on the Internet. Third, people are seeking guidance in individual as well as in collective memories of how these things were handled last time. Hence, they engage in telling stories, individually and collectively, of previous mechanical help-heart cases which they remembered, had read about, or heard about through hearsay. In fact, it is this storytelling that is the main property of these new sets of practices. The practice of storytelling is found in almost all of the new routines listed above – in education programs, in courses, and during rounds

and meetings. They are also a frequent theme of chatter in the nurses' station, during coffee and lunch breaks, during hand-over talks, examinations, and everywhere in the corridors.

In sum, a dramatic tension of life and death is always present in Heartlands. Upon the entrance of the HeartMate-patient, however, this drama grows stronger and seems more acute. The established order of everyday practices gets disturbed and all of the conventional daily rites are altered. The extraordinary character of the new circumstances – imminent death, state-of-the-art treatment, the latest technology, prominent expert knowledge, and multi-professional team work – provides Heartisans with space to increase the dramatization of the sense of danger and importance. The implantation of a mechanical help-heart is the kind of practice that makes the very grandeur of the Heartlands and of the Heartisan people. It is the performance of excellence, of the revered cutting-edge medical science and technological progress fused into one single ritual that is yet to be performed. It is what distinguishes the Heartlands from the rest of the hospital and also from many other hospitals. It is the practice that saves peoples' lives; it is the front line of the Heartisans' fight against death with the latest technology and best of expertise available. It is the exhibition of professional skills that Heartisans take much pride in – a medical parade that is not merely a matter-of-fact way of practicing medicine but instead is also highly ceremonial. The implicit effect that the sum of collective efforts and observable changes of daily practices in Heartlands have on Heartisans is "... to bring individuals together, to multiply the relations between them and to make them more intimate with one another", thus rousing what Durkheim termed *collective effervescence*¹²⁵, i.e. euphoria of the sense of belonging strengthening the team spirit, and rendering their adventures meaningful.

¹²⁵ Already mentioned earlier regarding the way that formalized discussion meetings help integrate the complex multi-professional setting (pp 213).

SUMMARY

Concepts of hope and compliance are made particularly explicit in preparation practices. During the third part of preparation the entire Heartlands is arranged and structured with the explicit aim of providing the best conditions possible for the implantation of a mechanical help-heart. The guidelines are revised and fine-tuned, staff is educated and coordinated. At the same time, through the intense social drama, brought about by the imminence of death, state-of-the-art treatment, advanced and sophisticated technology, prominent knowledge and multi-professional team-work, the sense of professional identity is reinforced. Organizing practices help establish a proper way of meeting the challenges brought with this particular treatment – and therefore also provide a foundation for the hope that is being provided to the patient. After being morally, physiologically, and technologically fine-tuned, and after the proper organizational measures had been taken and the sense of community had been reinforced, the patient and the Heartisans were now ready to get on with the core practice of the mechanical help-heart treatment – surgical implantation.

II OPERATION

THE SCENE OF OPERATION

The nurse who had been taking care of Bengt-Erik during the night turned around as she went out the door and said that she was going home now and that they'd meet again soon, after his operation. "Let's hope so", said Bengt-Erik. "I'm certain we will", she said, reassuringly.

It was about half past seven and still dark outside when I arrived at TICU on this particular morning. This was the big day, one of the biggest days in Bengt-Erik's life – it was the day on which he was going to get a mechanical help-heart implanted inside his chest. It was

also the day on which he will go through the treatment that he may survive... or not. No one knew. Everyone hoped.

Architecture of hope

Blue and green are the colors of the Department of Cardiothoracic and Vascular Surgery¹²⁶. Blue is usually the scrubs color of people working in the operating room – the nurses, surgeons, anesthesiologists, and perfusionists. Surgeons' and anesthesiologists' work includes, however, not only operations but they are also regularly scheduled to take care of ward work; surgeons are in charge of the Cardiothoracic Ward and anesthesiologists of TICU¹²⁷ and of SSDU¹²⁸ (see Figure 4). When working outside the operating room they should be wearing green gowns. Blue gowns symbolize a higher level of hygiene and should not be exposed to any risk of contamination by being worn outside the Thoracic Surgery area. During shorter errands outside the surgery area, a white coat should be worn, buttoned up well to protect the blue gown from contamination. Upon re-entry into the surgical area the white coat should be disposed of in the laundry bin. Indeterminacy in the threat of deadly infections is managed through these hygiene rules. This ceremonial way of managing indeterminacy through performative and complex relations between uniform color and space is a way of neutralizing threats to the success of the surgical procedure, thus contributing to the preservation of a sense of hope among staff, patients, and visitors alike.

These hygiene rules are, however, quite often a subject of individual interpretation – especially among anesthesiologists, some of whom seem to have embraced the blue gown as their only professional costume, even on days when they do not enter the surgical area. Although they would, at least most of the time, cover

¹²⁶ As opposed to the white gown so common one floor below at the Department of Cardiology.

¹²⁷ TICU = Thoracic Intensive Care Unit

¹²⁸ SSDU = Surgery Step-Down Unit

their blue costumes with a white coat – in accordance with hygiene rules – I have never seen some of these doctors in green or white gowns. Perhaps the individual sense of identity as a part of an operating team, and the prestige that is socially ascribed to this particular status position, is so appealing to some individuals that they find the green gown simply inapt – a cacophonous contradiction to their identity.

One of the cardiothoracic surgeons said that the sense of professional identity cannot be excluded as one of the possible reasons behind this kind of behavior. Moreover, while it is taboo to wear a blue gown outside the surgical area, especially if anyone exits the Cardiothoracic Department completely to attend a meeting in another department or to go to a hospital canteen to eat or to purchase a take-away lunch box, wearing a white coat over the blue gown provides the accepted way to lift the taboo. Here, the most apparent implication is the aspect of power inherent in uniform color rules: those who have access to the inaccessible chambers of the surgery area – the blue-uniformed people – also have the monopoly of total freedom of movement throughout the entire Heartlands, i.e. full access; all the others – the green- and white-uniformed people – have limited freedom of movement throughout the Heartlands, i.e. restricted access. In practice, this means two things. First, staff wearing green can move freely throughout the entire Department of Cardiothoracic and Vascular Surgery, which involves, first, the TICU, the SSDU, and the Cardiothoracic Ward. On exiting the Department of Cardiothoracic and Vascular Surgery they should wear white coats to avoid contaminating their green gowns. They are prohibited from accessing the surgery area. Second, staff wearing blue is restricted solely to the surgery area. However, many of them do move freely about the TICU and SSDU, as well and by putting on the white coat they lift the taboo and can be seen anywhere in the Heartlands. Except for white coats, a white gown is in general quite rare in the

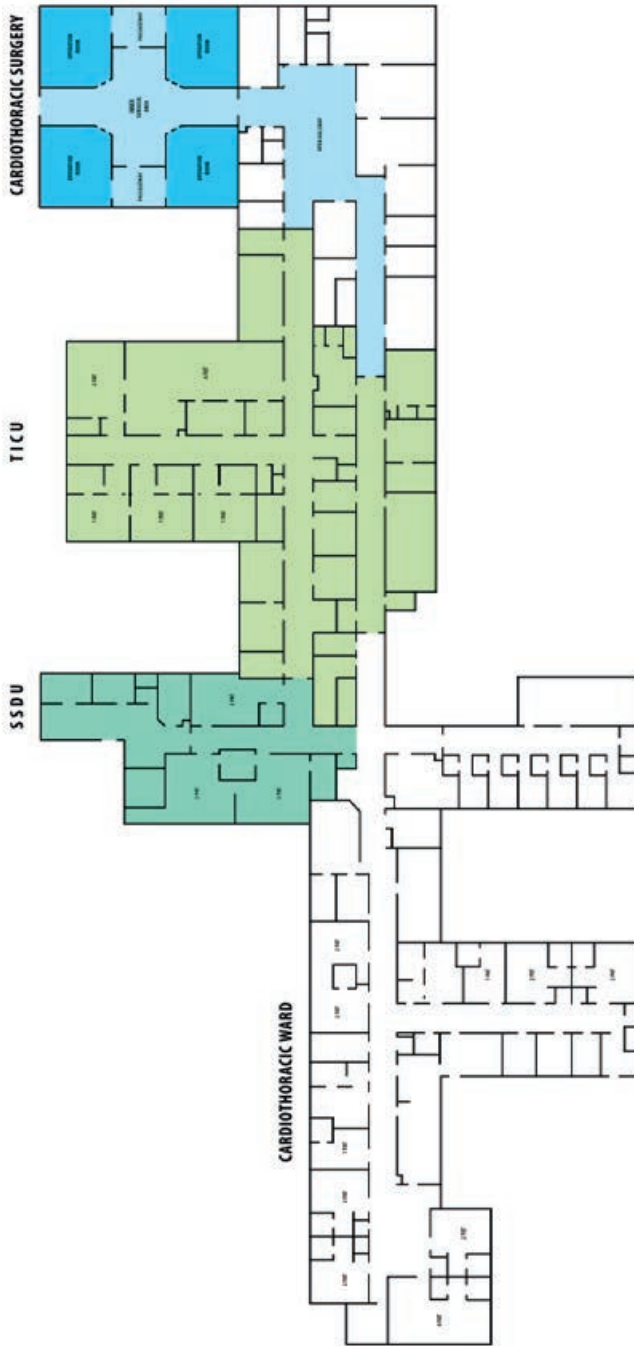


Figure 23: Department of Cardiothoracic Surgery

Department of Cardiothoracic and Vascular Surgery¹²⁹. Presence of colleagues wearing only white is noted immediately and is sometimes even joked about, as when four cardiologists appeared at the busy TICU nurses' station. All wearing white, they clearly stood out against the background of the green- and blue-dressed crowd. "Hey, now there's too many of you people here", Per the anesthesiologist was quick to point out in front of everybody, causing them all to laugh. "Well, if it weren't for us you'd have no job", responded one of the cardiologists quickly, smiling right back at Per. Although recognized as the apparel of the outsiders, white gowns are still tolerated throughout the corridors of TICU, SSDU, and the Cardiothoracic Ward. Entrance to the surgical area, however, is restricted to staff wearing blue gowns. This enacted distortion of hygiene rules, however, seems paradoxically enough to serve the same purpose – management of indeterminacy. This ceremonial way of reproducing professional identity, by putting up resistance to the requirements of the hygiene rules, provides some doctors with authority that others can never have. By bending the rules they are broadening their action-space in comparison to, for instance, that of their cardiologist colleagues. This allows for a hierarchical structure that allows order to be reinforced symbolically while at the same time avoiding direct confrontations among the colleagues.

Main site

There are places in Heartlands, however, where bending of established rules is not as easily tolerated. The closer to the core of the surgical area one gets, the more rigid are the restrictive entrance rules. The surgery area is isolated and secluded from the rest of the Heartlands, not only by the restrictive entrance rules, but by architectural design through which it is placed in isolation – it is

¹²⁹ Except for the Cardiothoracic Ward where nurses and assistant nurses are mainly dressed in white with just an occasional green cover. Doctors in charge – who are surgeons – when doing the ward work, wear white pants with green jackets in contrast to the all-blue gowns that they usually wear when operating.

placed on the third, i.e. the top floor and at the far south-east end of the building – which provides surgeons with a space surrounded by an aura of mystery and affords them, in addition to control over a patient's body, control over the conditions under which they work (Adams and Schlich 2006). Most of all, it provides them with that special power and status among the rest of the Heartisans.

Upon entering the open hallway all white coats must be removed and hung on the wall. This hallway, surrounded by spaces including storage rooms, changing rooms, offices, and a lunch/coffee room, works as a pit stop for anyone entering the inner part of the surgical area, with four doors leading into four different operation rooms. After being pre-medicated, patients are brought here on their beds and moved over to their operation gurneys. Here, the operation nurse and/or nurse anesthetist chit-chat with the patient, making jokes and trying to cheer him/her up before entering the operation room. A daily operating schedule is posted here as well as a monitor indicating the current status of all four operating rooms. Green plastic boxes hang on the wall containing new thin masks and head coverings which anyone heading for the inner part of surgical area is required to wear upon entering. Two crossed hallways separating four operation rooms make up the inner surgical area. In front of each operation room there are two large basins. Above each basin, soap and antiseptic liquid containers are mounted. Each basin is equipped with an almost half meter long tap handle that can be pushed with the elbow in order to start, increase, decrease, or shut off the flow of water. Surgeons carrying out and/or assisting the operation scrub their hands here before entering the operation room. The scrubbing is done by thorough and repeated rinsing and soaping of hands and lower arms up to elbows for a couple of minutes. Thereafter, the same skin surface is literally soaked in antiseptic liquid which is carefully rubbed in. After the scrubbing is completed, another swinging door, leading to a chamber that is actually a passageway into the operation room, is opened by a hip or by a shoulder with the now sterile hands and lower arms carefully carried in an upright position,



Figure 24: Cardiothoracic surgery areas in Heartlands

demonstratively detached from everything but air. The passageway is also used for preparation of items used in surgery – such as mechanical help-hearts, which are tested, sterilized, adequately preclotted¹³⁰, and prepared one last time here before being brought

¹³⁰ Preclotting is the practice where a patient's own blood is forced through the device prior to implantation to render the material temporarily impervious to blood.

inside the operating room and implanted into someone's chest. Patients don't go through this passageway but through another set of swinging doors leading straight from the inner part of the surgical area into the operating room. The patient is transported on the operation gurney, from the open hallway, through the inner part of the surgical area, and through the swinging doors straight into the operating room, accompanied by two anesthetist nurses and an anesthesiologist. Here, with an anesthesiologist on the patient's right and an anesthetist nurse on patient's left side, plus another anesthetist nurse standing just behind the patient's head, the patient is slowly put to sleep.

The anesthesiologist's role is essential for the performance of this procedure. In fact, it is so important that the procedure would be impossible without it. Anesthesiologists possess a particular kind of medical knowledge that enables them to prepare the site of the body properly, so that it can withstand the abuse of such violent treatment as open-heart surgery. It is their job to protect the patient from pain, suffering, and harm by conducting a series of practices. These include preoperative evaluation, consultation with the surgeon and the rest of the surgical team, and organization and execution of safe anesthesia delivery. The anesthesia is always custom-made for each individual. The job also includes systematic monitoring (observing the color of the patient's facial skin, palpating the patient's skin, regulating various processes regarding bodily fluids, monitoring respiratory functions, keeping an eye on the patient's blood flow and heart functions by ultra-sound and electrocardiograph technology), and providing life-support and continuous pain control. Ultimately, they are also in charge of the patient's post-operative treatment, while the patient's condition is not yet stabilized and risk of post-operative complications is high. In addition to protecting the patient from pain and harm, the anesthesiologists ensure that they wake up with their vital functions (such as breathing and blood flow) still intact. Nevertheless, as will be evident here, in spite of the major role that the anesthesiologists play in a mechanical help-heart implantation

procedure, it is the surgeons who are symbolically marked as the big stars of each performance.

After the patient is put to sleep, a white sheet that was used for covering the patient's naked body during the transfer to operating room is removed and the patient's entire body is soaped up, washed, and soaked in yellowish antiseptic solution. The patient is covered with green sterile sheets in the standard fashion, leaving only enough space on the patient's chest so that the operation can be performed. A green cloth is mounted above the patient's head so that the anesthetist team can monitor the patient's face throughout the operation, while the face remains invisible for the surgeon and assistants. The operating room is thus divided into two zones: one sterile (the patient's body and the space occupied by surgeons and scrub nurse) and one non-sterile (the patient's head, the anesthetist team area, and a perfusionist operating a heart-lung machine approximately one meter below patient's left foot). After the patient has been put to sleep and hidden behind the little green curtain, the surgeons enter the operating room.

SURGERY

Performers of hope

Being a surgeon is also being a performer (Katz 1999). The work of surgeons is visible; it is put on display and is thus also made into a subject for auditing on several levels (as in the critical gaze of an audience). First, the quality of their performance is visible to themselves and to one another as they perform the surgery. Second, it is also visible to the rest of the operating team. For instance, a successfully stopped bleeding is usually considered as a good performance while a punctured lung or forgotten scissors inside the cavity would probably be considered as not a bad performance. Furthermore, operation outcome statistics reveal the trend of each surgeon's performance. Thus, a series of time-efficient and successful operations during a certain period of time is regarded as good results, whereas a reoccurrence of lengthy operations marked with

complications and fatal losses is regarded as poor results. On a daily basis, surgeons negotiate between life and death with their hands. Each idea that becomes actualized in practice can be decisive and crucial... and beyond recall.



Figure 25: Implantation of a mechanical help-heart. From left: anesthesiologist, ethnographer, main surgeon, assisting surgeon, scrub nurse, perfusionist, circulating nurse, industry representative, another perfusionist (partial image). (Courtesy: Heartlands; reprinted with the kind permission of the participants).

To successfully open up a living human body and insert a mechanical device is in no way an easy task – especially not when the operation is done upon one of the most important of all the vital organs in human body, namely the heart. Just a slight mistake, a slip, or a lapse in focus can mean the difference between life and death – a burden of guilt that surgeons are forced to cope with. It is their responsibility to do a good job. A good job is a job done according to the rules of the job. Deviations from the proper conduct are

considered hazardous and must be avoided at any cost. The surgeons' habitus, i.e. embodied system of dispositions for thinking, acting, and orienting themselves in their social surrounding (Bourdieu 1977; Brody 1991[1990]), is exceptionally constricted during the operation. All the steps of the procedure are carefully planned and standardized into a strict succession of acts that must be followed, constituting a performance script with little room for improvisation. The sudden changes and unexpected turns in the course of things – complications such as organ or device failure – are not met with the confusion of anarchy and turmoil but are usually thought of beforehand and managed with a new set of proper actions. In other words, while surgical work does leave room for lateral thinking and creativity with which surgeons can manage the difficult and surprising situations – their freedom in the operation room is, however, highly conditioned and their improvisation highly regulated.

Moreover, as good or poor surgical performances are directly visible and measurable through the records of mortality and morbidity rates, they also shape the overall statistical profile of the whole departments and, ultimately, of the entire hospitals. Although surgeons are hardly ever alone held responsible for poor rates, nor are they ever alone explicitly honored for good rates, their professional lives and careers are nevertheless determined by these numbers. Ultimately, scars on a patients' skin are the subject of auditing and judging of the surgeon's performance as if they were surgeon's personal signatures; an ugly, uneven, or crooked scar can be judged as poor surgical performance while a thin, neat scar is often seen as a sign of surgical precision and professional excellence.

A surgeon's work involves long hours of intense focus while balancing, with someone else's life at stake, between life and death. This also implies the necessity of coping with a bizarre kind of responsibility with which most of us are unfamiliar. When I asked Lars, a heart surgeon, just minutes before he was to perform the implantation of a mechanical help-heart on Maja, what a surgeon does the night before such a complex operation as this one, he said,

“Nothing special”, adding that he stayed away from alcoholic beverages and that he usually doesn’t have problems falling asleep. “Of course”, he continued, “I’ve been thinking about it the whole weekend ... not that I was worried, but more so I can get in the right mood and focus”. When I posed the same question to another heart surgeon, young Doctor Fredrik, he said that he might have been nervous in the beginning of his training as a surgeon, the first couple of times, but that he nowadays is “simply focused and nothing else”. He also said, “It is really all about thorough preparations ... failing to prepare is to prepare for failure”. Fredrik emphasized also his role as a specialist: “And then again, I am a specialist... and as such I’m supposed to perform a standard procedure such as this one¹³¹ quite easily”. These answers reveal the heroic image of a surgeon as someone who is not worried or intimidated in any way by these things but is instead in charge and controlled, managing his emotional self by getting into the right mood and by being able to focus and perform when his skills are called for. This self-image of a surgeon as the professional who is running things could also be observed during the visit that Doctor Lars paid to both mechanical help-heart patients just before they were transported to the operation room. In the case of Bengt-Erik, Doctor Lars wished him good luck and added: “Now we’re on it and we’re rolling! See you after the operation! [*Nu kör vi, så vi ses efteråt*]”. In Maja’s case, he asked her if she had any questions before the operation. Maya said she didn’t and Doctor Lars ended their brief conversation with a cheery greeting: “Alrighty then... then we’re on it and we’re rolling [*Vi kör så det ryker!*]”. The emphasis in this brief pep-talk is put on the assuring reference to the future as certain and bound to take place while the eventual problems, complications, and things that can go wrong are just simply overlooked. This is the time for hope and doubt has no place here. Moreover, ‘rolling’, derived from the Swedish *Vi kör* [literally, ‘we are driving’ or ‘we drive’] indicates that things are already in motion. *Vi*

¹³¹ Just minutes before our conversation I had the opportunity to observe Fredrik as he performed a bypass surgery.

kör means also more than merely ‘rolling’ as it also denotes being in control of the things in motion – hence the ‘we’re on it’ translation. This expression creates an image of a surgeon as a solid and balanced performer who is in control, and this image was communicated to the patients before the operation. What’s more, the surgeon’s use of ‘we’ also provides the patient with the dignity of actorship – as the one ‘rolling’ shoulder to shoulder with the unwavering surgeon.

Performance of hope

Surgeons are always the last ones to enter the operating room while ceremonially air drying their water- and alcohol-drenched hands by waving them high up in the air. This drying ‘dance’ is multivocal: i) it makes sure surgeons don’t touch any non-sterile objects, including their own and other people’s bodies and gowns; ii) its end signals to the scrub nurse that she can now help them put on a sterile blue gown; iii) weaving signals to the rest of the team that the important rules of scrubbing have been observed and that surgeons are not to be physically approached; iv) the normative value of the importance of the rules of hygiene is reinforced through its performance; v) the surgeons’ late entrance signals that they are headlining this particular performance.

Surgeons’ clothes differ from everyone else’s. Upon entrance they are already wearing their balaclava-like headgear, which covers everything but their eyes. Furthermore, they are crowned with a special set of microscope-enhanced eyeglasses, i.e. surgical loupes or surgical telescopes, equipped with small but powerful flashlight mounted on their foreheads. From this light on their forehead two white cords stretch and encircle their heads until they merge again into one single white cord, which is then plugged into a machine that supplies their headlamps with power, giving them an aura of cyborgs mediating the power of high-tech medicine. This head-mounted vision technology enhances surgeons’ vision by enabling them to see what they otherwise could not. Moreover, in addition to empowering them with vision superior to the rest of the operation staff, it makes their

appearance indisputably ceremonial. When surgeons estimate that their hands are sufficiently dry they stop the weaving and approach the scrub nurse with their hands held out in front of them. The nurse holds up a sterile blue gown, through the sleeves of which the surgeons insert their hands. Then they turn around and the scrub nurse ties the gown behind their backs. Thereafter, the scrub nurse also helps them to put a double pair of sterile rubber gloves on each hand. When all this is completed, surgeons are considered ready to start performing.

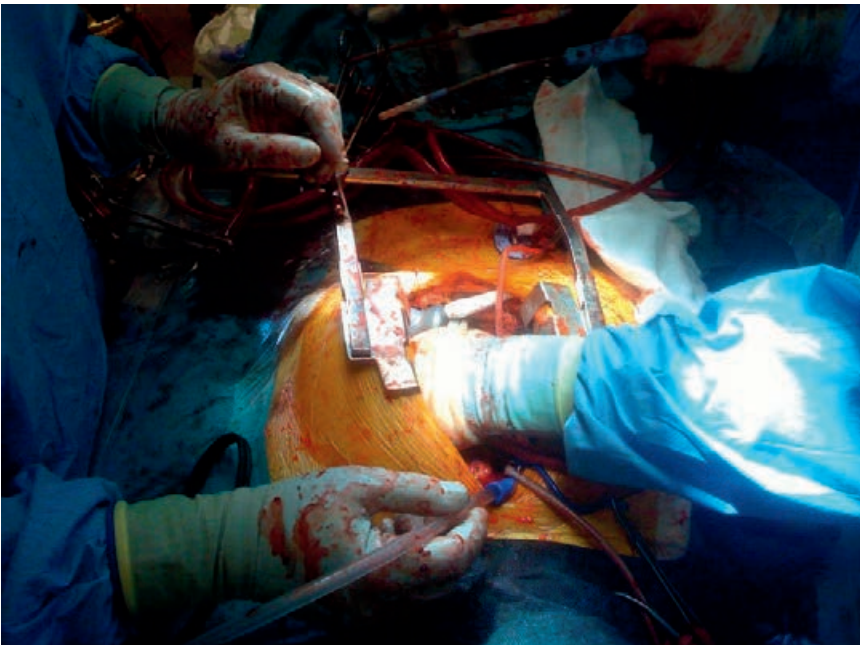


Figure 26: A look at the surgeons' 'hands-on' performance from the "ringside seats" perspective. (Courtesy: Heartlands; reprinted with the kind permission of the participants).

After the final steps of preparation procedures have been brought to an end, the surgeons position themselves right beside the patient and lean over the still visible part of the patient's chest, i.e. the actual space where the surgery is about to be performed. The anesthesia team has already assumed their position behind the green

curtain, just behind the patient's head, and from there they monitor and control the patient's status and vital functions. I remember asking the anesthetist nurse, just minutes before the first time I was going to observe open-heart surgery, how close I am going to get and how much I am going to be able to see. "Oh, don't worry, you'll be right there with us in the anesthesia team, it's the ringside seats (*första parkett*), the best you can get!", she said. Once again, I realized that the surgeons are the ones on the other side of the curtain, on the stage, performing in the middle of the ring, where the action is.

Although the rest of the operating team members also play their specific roles in this performance, they still regard themselves as, at least partially, spectators of what is taking place at the core of the surgery – rather like participating observers of the surgeons' handicraft. First, before Bengt-Erik's chest was split open, he was, as a safety measure, prepared for connection to a heart-lung machine. Doctor Per explained that this machine, which is a standardized part of heart surgery, enables extracorporeal circulation of blood and oxygen and will be used while the chambers of Bengt-Erik's heart are being cut through and opened. Moreover, as Bengt-Erik has had one heart surgery before there is a significant risk of right-chamber failure during the surgery. If this were to happen, the heart-lung machine can be used right away, which is why it is made ready and connected to the patient in this early phase of surgery. Doctor Lars has cut an approximately 10 cm long incision in Bengt-Erik's right groin. Doctor Karl used a small retractor made of stainless steel to keep the incision open. Doctor Per expressed his worries about "the garden hose", as he refers to Bengt-Erik's inferior vena cava, the vein that carries blood from the lower parts of the body into the right atrium of the heart. While monitoring this vein on the ultra-sound screen Doctor Per said that it is "much too large" but that all the signs and the overall prognosis are still quite good. Doctor Lars has now entered the incision in Bengt-Erik's right groin with long tweezers and a grip. A plastic pipe, resembling a straw, was secured with sutures to a vein and to an artery inside the groin. Two thick plastic tubes – which

actually do look like garden hoses – were carefully arranged over Bengt-Erik’s body, where they were put in order for use. One of two thick tubes was now pushed into the incision in the groin, through the body, and all the way to the right atrium. Doctor Per was monitoring the procedure with the ultra-sound apparatus and navigating: “You’ll have to go back a bit!”. Then he once again showed Bengt-Erik’s “garden hose” to me and explained that it is now 3.1 cm in diameter while normally it should be between 1.5 to 2.5 cm. Bengt-Erik’s right atrium is also much too large, said Per, and “should normally be 40 mm in diameter, but his is 72”.

A squirt of blood shot out from the tube in the groin, over Bengt-Erik’s right thigh, and hit the scrub nurse’s belly. Some of the blood splashed down below Bengt-Erik’s knee and on his leg. Doctor Karl noticed the leak and tightened the tubes by sewing up a couple of sutures.

Doctor Lars placed all ten fingertips onto Bengt-Erik’s chest and made a couple of pushing movements, making the chest sway from side to side. The investigative manner in which Doctor Lars used his fingertips for sensing the anatomical structure of Bengt-Erik’s chest exemplified how the hands can be used to enhance vision, enabling the surgeon to get familiar with the body that he was about to cut open. The scrub nurse then placed a small, slim, thin-bladed knife in the palm of Doctor Lars’ hand without being prompted by the ceremonial “Scalpell!” order that surgeons always make in movies, as a fanfare that cuts through the air, pronouncing the operation ritual officially opened. Here, this was just another amongst the many other embodied parts of the operation ritual that didn’t need any words. As such it had its given place in the succession of actions that this kind of operation is composed of – a part of routinized flow.

Doctor Lars took the knife and sliced through the layers of Bengt-Erik’s skin and flesh with one accurate and steady move. Blood poured out. Absorbent white cloths were used to soak up the blood. The assistant surgeon, Doctor Karl, burned the numerous bleeding vessels with an electrically heated metal pen-like object to minimize

the bleeding – a procedure called ‘cauterization’. Thin strips of bluish smoke rose from the burned vessels, carrying a quite distinct and unpleasant odor of burnt human flesh. Doctor Lars punched a hole just beneath the sternum (the breastbone connecting the ribs). He then shoved his index finger inside the hole in order to orient himself and establish the exact location of the opening. This was the second time a surgeon used palpation to establish a point of spatial anatomical reference prior to proceeding to the next step.

The scrub nurse carefully placed a pistol-like electric saw, a ‘sternum saw’ with a toothed blade, into the palm of the surgeon’s hand. “Now we can go on the machine!”, said Doctor Lars and the perfusionist responded by turning the heart-lung machine on. The anesthetist nurse made a note of the exact time when the patient “went on” the heart-lung machine. An ominously loud, piercing, noise filled the operation room; surgeon Lars positioned the toothed blade in the pre-punched hole and pushed the saw against the sternum, causing the sound frequency to oscillate from a lower pitch when the saw was idling to the higher pitch when it was forced against the bone. Splinters of bone matter hit the air. After five to fifteen seconds, Bengt-Erik’s chest was sawn in two. Lars then cauterized the area underneath that half of the sternum which is located on the opposite side of the patient, closer to the assisting surgeon Doctor Karl, who helped Lars by holding that side of the patient’s chest up with the help of two stainless steel rakes. When the surgeon finished, they switched roles and the assistant did the cauterizing while the surgeon held the patient’s chest up for him. A sternal retractor, a stainless steel device, was then placed inside the crack in Bengt-Erik’s breastbone and was expanded to separate the rib cage and reveal the vibrant inner body. A suction pump was used to dispose of the excess blood. Again, a cauterizer was used to cut through the pericardium in order to reveal the patient’s heart.

Bengt-Erik had already been through one open-heart surgery before, which had caused his pericardium to grow together with his heart as a scar tissue. Therefore the surgeons must first go through a



Figure 27: Scrub nurses sterile surgical instrument table. (Courtesy: Heartlands; reprinted with the kind permission of the participants).

meticulous and time-consuming procedure of separating the pericardium from Bengt-Erik's heart before they can start with the implantation procedure. This was done in a fashion similar to that where surgeons helped each other while cauterizing in order to reduce the bleeding (see above). Also this time the cauterization was performed – but instead of being used as a technique to stop the bleeding, this time pericardium tissue was burnt off in order to separate it from the heart. The first to cauterize was Doctor Karl while Doctor Lars held the thin sheet of pericardium up with a pair of tweezers, and then they switched their roles. Doctor Karl repeatedly pushed his entire hand inside Bengt-Erik's chest and underneath his heart to feel how the work he and Doctor Lars are doing inside Bengt-Erik's body was progressing. This was the third time a surgeon used his hands to 'see' what his eyes could not. Then they switched roles and Doctor Lars did the cauterizing while Doctor Karl held up

the pericardium. Doctor Lars also used his hand to orient himself inside the patient's body. This was the fourth time that I have observed this particular practice.

One of the larger vessels started bleeding and cauterization could not stop the bleeding. Doctor Lars sewed it up and the separation of pericardium from the heart could continue. Doctor Per, the anesthesiologist, leaned over the blue head-curtain and asked the surgeons how things are going. "Well, there is quite a lot that needs to be solved but we're doing fine", said Doctor Karl. "Yes, we are the real problem-solvers!", responded Per. It seemed, during this stage of the operation, that only five out of nine people who were present in the room (not including myself) were actually participating in operation work: two surgeons, the scrub nurse, one of the two perfusionists and also one of the two anesthesiologists. At the same time, two anesthetist nurses were behind me chatting, as were also the two surgery nurses on the other side at Bengt-Erik's feet. The second anesthesiologist, Doctor Pia, had left the operation room, whereas the second perfusionist was strolling around in the operation room just checking things out with no particular agenda linked to the operation that is being performed. Throughout the entire course of the operation it was only the surgeons and a scrub nurse who were always in the middle of the action. Other team members enjoy the comfort of relieving each other, leaving the operation room to rest, eat a snack, drink some water or coffee, or go to the restroom.

In order for the mechanical help-heart to be attached to the heart's left ventricle, a round hole – about the size of a nickel – must be cut into a heart muscle so that the ventricular cavity can be entered. The position of the hole needs to be just next to the septum without involving it. Involving the septum would damage it severely, while a hole that is too far from the septum would not allow the mechanical help-heart's inflow conduit to be positioned accurately. Therefore, a careful procedure and technological assistance is used to ensure that the heart is cut open properly.

Surgeon Lars marked the apex with a light pressure of his fingertip while anesthesiologist Per monitored his palpation with ultra-sound. Once again, the surgeon used his hands as navigation – this time in collaboration with an anesthesiologist and an ultra-sound machine. When the pressure, which is clearly visible on the screen of ultra-sound machine, was observable just above the apex on the left side of the septum, anesthesiologist Per gave a signal to Lars who then used a coring knife, actually a sharp metal pipe, pressing it against the marked spot on the apex and with circular movements cutting through the heart. Blood poured out of the cavity. A small plastic pipe – the apical sewing ring – is then sewn to the hole. This turned out to be quite a complicated and time consuming procedure.

The key is to make the sewing ring firm and static so that the inflow conduit of the mechanical help-heart can be attached to it properly, preventing any chances of leakage. A number of needles and sutures (perhaps two dozen) surrounded the edge of the round cavity – each suture was sewn through the heart muscle along the rim of the hole and then through the sewing ring and out again. Each sewn suture was placed aside by the assistant surgeon and when a half circle of sutures was done the strings were carefully pulled, securing half of the sewing ring to the hole. The sutures were then fixed with a pincer and the other half circle was sewn. A small white patch was attached to the end of each suture that was being sewn to the heart.

Doctor Karl was holding all the sutures in his hands, stretching them and making sure they didn't get tangled. After this all the sutures were pulled simultaneously, making the sewing ring sink deeper into the hole in the heart. The sutures were then tied one by one with several knots on each one, then the inflow conduit was sewn onto the secured apical sewing ring. Finally, 'bioglue' was applied around the sutured edge of the sewn-up sewing ring to fasten the tissue. Then, Doctor Lars took the mechanical help-heart from its pan of salt-solution and attached it to the inflow conduit, using the sutures as well as the machine-applied plastic rings. He then shoved his finger under Bengt-Erik's skin and flesh and palpated for a while in order to

orient himself before making the tunnel for the drive line exit. Again, a surgeon uses his hands as an orientation instrument. Doctor Karl pushed scissors under the patient's diaphragm, through the abdominal fat, to a cross which Lars had just drawn on Bengt-Erik's abdomen, to the right of his navel. Doctor Lars made a circular incision at the drive line's exit site. For this he used the pipe-like knife, similar to the one used to perforate the apex, only significantly smaller in diameter. A drive line was attached to an enormous needle, which was then used to make a tunnel through the tissue by 'blunt dissection', i.e. separating tissues along natural cleavage lines (without cutting) and exit was made through the previously made circular incision. As the head of the needle appeared at the exit-hole, Doctor Lars got a firm grip on it and pulled it out together with the drive line.

After the drive line and the inflow conduit were secured it was time to connect the pump with a plastic pipe – no thicker than a finger – to the ascending aorta. Doctor Lars made an incision in the aorta (aortic anastomosis) and then cut the hole a bit wider with a pair of special scissors. The graft – a plastic pipe – was then sewn onto the ascending aorta.

A great deal of the action taking place in the operating room seems to follow the flow of embodied routines. Verbal communication is clearly not the principal way of communicating here. Indeed, the absolute majority of dealings are non-verbal, firmly ascertained through the standardized order of action.

At 13.27 the mechanical help-heart was implanted and perfusionist Roffe turned the pump on with the help of the computer-like control unit placed on the cart just next to the heart-lung machine. The mechanical help-heart started spinning. Bengt-Erik's chest was still wide open. At 13.31 the heart-lung machine was stopped; spatial reshuffling of the mechanically propelled blood flow was taking place. Bengt-Erik was no longer "on machine" – the machine was now inside him. Doctor Lars initiated the removal of the groin cannula acknowledging, "So, we are winding up the groin cannula... and now we are no longer in control of the rest!".

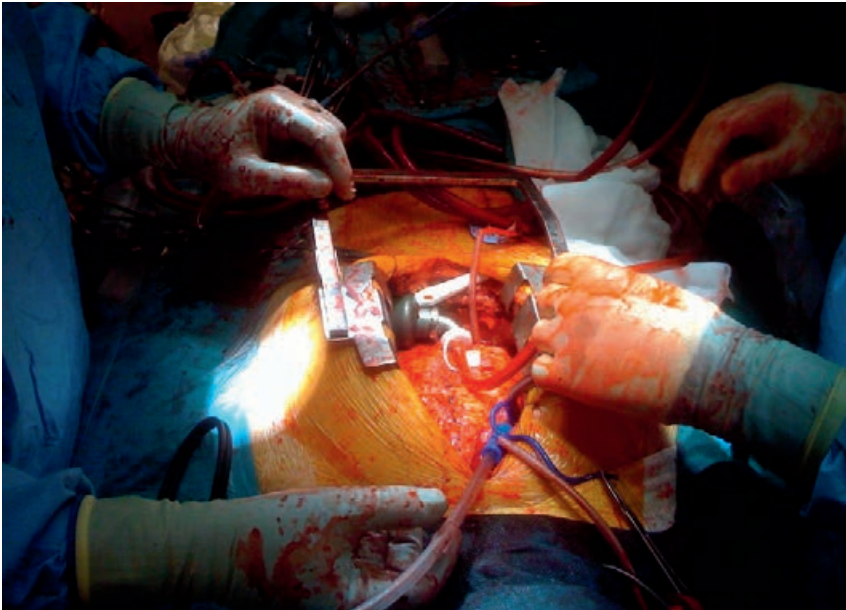


Figure 28: The implanted mechanical help-heart. (Courtesy: Heartlands; reprinted with the kind permission of the participants).

Just then he noticed that there was something wrong with Bengt-Erik's left ventricle. Anesthesiologist Per agreed. Suddenly, the alarm on the echocardiograph went on, signaling arrhythmia. The surgeons immediately gave an order for Doctors Jörgen¹³² and Viktor¹³³ to be called. The arrhythmia ceased by itself but returned again after just a couple of seconds.

Sten, an industry representative who was also attending the implantation, turned to me explaining how critical this situation was. Things can take sudden turns, he said, and an arrhythmia can cause the preload to the left-chamber to decrease, reducing the blood volume inside the chamber. As the mechanical help-heart is on now, sucking the blood out of the left ventricle, there is a risk that it might suck in air as the blood volume has decreased and the chest is still wide open. Sucking in air in the blood flow would be a disaster: "He

¹³² A professor in cardiology specialized in heart failure.

¹³³ A cardiologist specialized in pacemaker technology.

would die at once!”. That was why Sten ran to the control unit’s “off” button to shut the pump down in case the arrhythmia didn’t cease. While Sten was explaining this, pacemaker specialist Viktor entered the operation room. It turned out, however, that he was not of much help because the arrhythmia had nothing to do with Bengt-Erik’s pacemaker.

This episode makes clear how the rigid steps of surgical procedure are vulnerable to the unpredictable nature of the human body. The routine was disturbed and the course of action was suddenly punctuated by gaps of ambiguity and indeterminacy; the stability of structured *flow* turned suddenly into the volatility of unexpected *flux*. Thus, an attempt to establish a new order was immediately made as the two specialist doctors were called for. The primary flow was put on hold and the secondary one was engaged to close the newly-emerged gaps of indeterminacy. The sense of hope was threatened and in need of protection.

Bengt-Erik was steadily being filled up with blood. First, he was getting back his own blood that he had lost during the operation; it had been absorbed by numerous sheets of absorbent white cloths, which were now wrung out back into the heart-lung machine. A suction pump was also used throughout the entire procedure to suck out the blood and transport it to the heart-lung machine. Second, he received the units of blood from the blood-bank. His mechanical help-heart was now running at 7600 rpm.

After this it was time for Bengt-Erik’s chest to be closed and sewn up. First the breastbone was sewn up with steel wire. Both surgeons worked together to do this. A bleeding from the right side of Bengt-Erik’s chest was stopped as Doctor Karl sutured the bleeding vessel. Doctor Jörgen – a heart failure specialist – entered the operating room. Karl explained to him that the crises now were over but that his response was appreciated in any case. Eight pieces of steel wire about 40 cm long were now put through Bengt-Erik’s chest with sixteen pincers gripping the ends of each wire. The surgeons tightened each suture by joining and twisting the ends of each wire

together in a swirl, putting the chest back together. Thereafter the loose ends of the wires were clipped off and both surgeons sutured the remaining flesh and skin tissue. Thus the order of suturing is: i) bone; ii) flesh and subcutaneous tissue; and iii) skin tissue. The skin was, however, not perforated by the needle. Instead, the surgeons sutured the subcutaneous tissue so close to the outmost layer of the skin that it left only a thin line with no sutures visible, aiming for a minimal scar – a perfect signature of a skilled surgeon. First to leave was Doctor Karl at 15.10.

Doctor Lars continued and tied the last suture, and at 15.17 he turned to the anesthesiologist Per and said: “Thank you for good teamwork!”. “Yes, thank you!”, responded Doctor Per and then Lars left the operating room. After Lars had left the room Doctor Per started praising him, “It is so nice working with Lars!”. “Yes, everything goes so smoothly!”, added the scrub nurse, nodding in agreement.

At 15.20 Bengt-Erik’s chest was together again and the operation wound was neatly dressed by the scrub nurse. At 15.35 the scrub nurse had completed dressing the drainage tubes and the driveline sticking out of Bengt-Erik’s body. Anesthesiologist Per switched Bengt-Erik’s respirator from stationary to mobile and at 15.48 he was transported out of the operating room by three nurses, two of whom pushed the bed while the third pushed the mobile respirator. The second anesthesiologist, Doctor Pia, joined the entourage. At 15.52, Bengt-Erik arrived in room 12 at TICU, surrounded by approximately 10 persons, three of whom were doctors and the rest nurses and assistant nurses. Because of all the tubes and wires connecting Bengt-Erik to different devices it was quite difficult to move him from the operating gurney to his bed. At 15.58 Bengt-Erik was lying in room 12 in TICU. His mechanical help-heart was powered by two batteries during the transport from the operating room but was now connected to the stationary power base unit (PBU). All the tubes and wires were now connected to stationary units in the room such as the respirator and echocardiography. Anesthesiologist Per arrived again with the



Figure 29: Scrub nurse dressing the wound, the drainage tubes, and the driveline cord.
(Courtesy: Heartlands; reprinted with the kind permission of the participants).

ultra-sound cart and performed an ultra-sound examination to monitor the effect that the mechanical help-heart was having on Bengt-Erik thus far. Based on the examination, he concluded that the left ventricle is not yet sufficiently relieved by the pump and that the number of revolutions, thus, should be increased. Perfusionist Roffe, who was also there, increased the pump speed from 7600 to 8000 rpm.

Now Lars, the surgeon, also arrived and asked Per about the situation regarding the post-operative internal bleeding. “Well, they’ve been filling up, answered Doctor Per pointing to the two plastic drainage bags. “Yeah, well”, Doctor Lars said, “we’ll see”. A pacemaker specialist, Doctor Viktor, also entered the room with his pacemaker machine cart to fine-tune Bengt-Erik’s pacemaker and to turn the defibrillator function back on¹³⁴. At 17.00 it was still quite

¹³⁴ Which was turned off during the operation.

crowded in room 12. A continuous stream of people entered and left the room. One nurse and one assistant nurse stayed there the entire time. They were the ones watching over and taking care of Bengt-Erik until the night shift arrived. Bengt-Erik was still asleep, as he was going to be for the next couple of days.

Performing Comedy

Joking was quite a common practice, not only in the operating room, but throughout all of Heartlands. It acted as a way to manage the tension inherent in work with such high stakes. As it was not regulated, joking was always informal in its very essence, but nevertheless welcomed or expected by most as a regular ingredient in the majority of clinical practices – especially the surgery, which is probably the most dangerous and dramatic of them all.

Carried on the wings of a joke, sentiments are brought forward, turned upside down, ridiculed, celebrated and/or trivialized – the ordinary is made extraordinary and vice versa. Joking is done through metaphoric expressions, bizarre connotative insinuations, and double meanings. A patient is said to be “drowning” in edema; the heart is referred to as “the most beautiful thing one can ever see”, or as “weak” and “lonely without the medications”, or “like a house with upper and ground floor level”, or “of a size of a football”. The medications are referred to as “spices” (*krjddor*), or as a “Rolls Royce”¹³⁵. Disease is ascribed animate attributes as it is said to be able to “grab hold of” or “release” someone, or that it can “come” and “go away”; or it is described as a journey, or as a sports event such as a “race”, a “martial art” or just a “fight”. The word “anesthetic” (*bedövning*) was through deliberate use of connotative alliteration voiced as “grief” (*bedrövelse*). The body is described as something/someone you can pose questions to – “why don’t we ask your body?” or something that is able to think and share its thoughts, “we’ll see what your body thinks about that”. Body parts are reified through metaphors as when the Vena Cava was addressed as “a

¹³⁵ One of the most luxurious automobiles.

garden hose” due to its unusual size. The body is sometimes referred to as a “pincushion” while the heart is regularly referred to as “a pump”.

Perhaps one of the most bizarre jokes that I have witnessed was one made by a heart surgeon during a bypass surgery. The wide-open chest and the beating heart of a man in his late fifties was the only thing standing between middle-aged surgeon Doctor Jan-Erik and me. Holding the artery between his thumb and his forefinger, the same artery that he just had cut open, Jan-Erik gave me this sly look straight into my eyes, as if he’s onto something impish, and asked me a question that I never could have imagined that I’d ever hear: “Wanna see an artery?”. Not quite grasping what he meant, I gave a nod of approval, more by inertia. Jan-Erik then released his grip of the artery and blood started shooting in an even steady stream from the hole he had cut in it just seconds ago and up in the air until it reached a height of approximately half a meter and gravity finally dragged it back inside the patient’s gaping chest: “So! Now you’ve seen one!”, he said cheerfully.

I was completely shocked. Patient’s heart was not beating any more. Jan-Erik and Yao Ming [a guest surgeon from China who was assisting Jan-Erik on this day] shoved their hands inside the patient’s chest and twisted and turned his heart. The heart flickered a couple of times before it stopped beating completely. The ECG graph was flat now, just like in the movies. The heart-lung machine now took care of the patient’s circulation and breathing. The heart was cooled down with a cold liquid [water?] which the nurse was poured over it every now and then. Some crushed ice was placed inside the cavity, around and underneath the heart, just before the heart-lung machine was about to take over. Jan-Erik looked at me as if to ask for attention, and said: “This is the artery in the heart...”, then he made a cut in the heart muscle with his scalpel adding: “... and now it’s an artery with a hole in it”. Jan-Erik laughed. So did everyone else in the room.

Joking in the operating room has been reported in other studies as a common phenomenon. Pearl Katz argued that ritualization of

surgery contributes to the overall efficiency of this highly technical and goal-oriented clinical practice "... by permitting autonomy of action to the participants and enabling them to function in circumstances of ambiguity" (1981: 336). Katz asserts that it is joking that allows for such a sense of autonomy to take place among the participants. She also claims that joking and small talk are confined to phases in-between ritually ordered sequences of behavior as free zones of autonomy and are not done during the more dangerous parts of an operation (1999: 198). However, joking in the operating room in the episode just described occurred during the "excision [and] repair", which Katz considers to be "the most dangerous parts of the operation" (1981: 348). In contrast to Katz's observations, my data seem to point in the opposite direction; joking was most often randomly interwoven and scattered throughout the entire operation and on occasion it was even intensified during these most dangerous parts of the operation. These periods of cutting and bleeding were when the surgeon used to joke the most, combined with educational remarks addressed to me, the audience, about each step of the operation. This was also the case during other heart operations that I have observed in Heartlands, although it needs to be mentioned that the degree of joking varied strongly between different surgeons. The common thing for them all was that there were phases when silence and tension dominated the room and then there were also phases when joking and small talk would take over. However, my data shows no evidence of any necessary connection of these phases to the structural ordering of the stages of operating ritual. If anything, such connection seems, vaguely, to be pointing to increased joking during the complex parts of the surgery, as if their purpose was to make a travesty of the ordinary/extraordinary order of things. The extraordinary miracle of surgery was trivialized as tamed and mastered by the hand of a skilled surgeon while the ordinary guy-next-door, who is down-to-earth, jokes and makes small talk, is in fact putting on a performance of his extraordinary mastery of the surgery. Or in a word, joking in the operating room seems to be more about adding to

the performance of a surgeon, and thus also to the performance of a rest of the team, which everyone seemed to welcome.

SUMMARY

Surgical implantation of a mechanical help-heart is a performance; it is performed by carefully casted actors – the operating team – for a targeted audience. This audience includes primarily the operating team itself, along with the possible spectators such as observing novice doctors and nurses, medical students through live surgery session broadcast on video conferencing, local, regional, national, continental, and intercontinental auditors of morbidity and mortality trends of each operating center, and so on. It is played according to a specified script (general surgery practice guidelines and particular formalized steps of mechanical help-heart surgery). This script is written by an authoritative playwright (the assembled body of medical knowledge produced as synthesis of results of ‘leading’ continuous experimental implantations of mechanical help-hearts). As a performance, then, it contains elements of drama (the tension of balancing between life and death), tragedy (unforeseen accidents and errors with potentially catastrophic consequences), and comedy (joking), which it communicates to its audience. However, not all of these three elements are addressed equally in this communication. For instance, rather than being explicitly emphasized through performance, the element of tragedy is strategically downplayed as a subject under the control of skilled doctors. What is instead dramaturgically accentuated is the image of a fearless surgeon who is in control, emotionally untouchable, able to focus and perform whenever duty calls. Through this drama, a self-image of a surgeon as the professional who is running things is communicated. Moreover, the life vs. death drama is given no more dramaturgical significance than is lent by the nature of the situation itself. In contrast, comedy is performed both as a way to enhance the heroic image of skilled professionals and also as a way to downplay the significance that various threatening hazards might have for the outcome of the

surgery. Comedy communicates self-control and bravery in the face of danger and helps alleviate the tensions inherent in the indeterminacy of a hazardous situation such as open-heart surgery.

There is more to the performance of mechanical help-heart implantation than being merely a role-playing before an audience. First, it is a way of ordering the practices so as to reflect the culturally deeply rooted Heartisan understanding of health/illness, life/death, body/machine, and other dualisms at play here. Hence, to perform the implantation of a mechanical help-heart is to adhere to the form of a Heartisan worldview. It is also instrumental, as it is used as a means of bringing about certain change – to implant the machine without ‘losing’ the patient and to ultimately reverse the negative trend of the patient’s heart condition, thus providing hope for revival. In conclusion, these three qualities – communication, formality and instrumentality – inherent to performances of mechanical help-heart implantation, confine them to a particular group of people and to a particular setting. On the one hand, a sudden introduction of alternative forms (for instance theatrical scripts instead of experimentally generated medical evidence) and/or alternative actors (theatrical actors instead of doctors and nurses) would destroy any chances for achieving the desired effect of implantation. On the other hand, lack of aesthetic ways of maintaining professional status and identity, and also amplifying the sense of community, i.e. rousing the collective effervescence, would in all probability drain the practice of its meaning for those involved. Thus, the instrumentality, communication, and formality of the implantation of a mechanical help-heart make it a culturally specific ritual performance.

III POST-OPERATIVE TREATMENT AND CARE

AWAKENING

The doctor says I look better now... but I don't feel that way.

MECHANICAL HELP-HEART PATIENT ON THE SIXTH DAY AFTER IMPLANTATION

Post-operative treatment and care consists of two stages: i) the TICU stage, and ii) the Heart Failure Ward stage. The entire period is a state of alert where nonstop attention is paid to the details of the patient's condition. Monitoring (clinical and technological) is intensive and central to the practice. The TICU stage is markedly more intensive than the Heart Failure Ward stage. Here, the patient is attached to a variety of high-tech machines¹³⁶ while blood tests are taken and ultra-sound examinations are performed daily. The staff perform their daily routines while being on constant stand-by to manage the oscillations and uncertainty of the ever-changing situation. Each crisis is responded to in accordance with the already determined sets of proper actions. During the calm periods in between the 'hot' peaks, things go back to normal and the standard care routines continue. For instance, a crisis caused by the excess of fluid in the lungs is usually handled by calling a radiologist (and at times also an anesthesiologist) who will use two plastic tubes, push them through the holes that had been cut out in the patient's skin and flesh with a sharp knife, shove them further between the ribs and straight into the lungs to drain the fluid out while the entire process is monitored on the ultra-sound

¹³⁶ Besides being connected to a stationary Power Base Unit (PBU) – with a system monitor and display module where the blood flow (litres per minute), pump speed (revolutions per minute), pulse index (left ventricular preload and pump speed ratio), and pump power (watts) can be monitored. The PBU is now part of his or her new life with a mechanical help-heart. The patient is also attached to an electrocardiograph machine, a respirator, etc. At times, a patient might be using several machines simultaneously, such as 1) a mechanical help-heart, 2) a pacemaker, 3) a pacing system programmer, 4) a multi-parameter patient monitor displaying oxygen saturation, pulse etc., 5) an ultra-sound machine, and 6) a multiple injector drug infusion system.

screen. A crisis caused by an event like atrial fibrillation is handled with cardioversion, which is usually performed by an anesthesiologist. A crisis caused by infection is managed with the help of antibiotics. A crisis caused by sudden pump failure is managed with strict guidelines for the proper set of actions that need to be taken. Thus, the standard post-operative care ritual is backed up with an arsenal of powerful rites on stand-by for whenever an emergency occurs.

During the first couple of days after the operation the patient transits from deep sedated sleep to being fully awake. This is a gradual process during which the patient most of the time is neither completely asleep nor wide awake but is literally caught ‘betwixt –and–between’ these two states¹³⁷. Everything that is done is also noted in a journal so that the next shift can be informed of the process and also so that the process can be audited. Meanwhile, the post-operative care is performed according to formal routines. Excess saliva is suctioned from the patient’s throat; the patient is given various medications; the drive-line is cleaned and dressed; the patient is checked on and monitored; a morning wash is performed, and morning and evening toilet visits are assisted; a male patient is shaved regularly; the staff palpate the patient’s legs and feet to check for temperature changes as indicators of changes in blood circulation; the patient is tube-fed with, for instance, a rosehip soup or mashed and pressed vegetables, etc. There are times during this kind of treatment, however, when nothing goes on at all and the staff watching over the patient would just hang around or use this time to attend to other tasks such as scrubbing the floor, or writing the journal.

The patient’s condition in the aftermath of the implantation of a mechanical help-heart is often rather unstable, oscillating from ‘things are going as planned’ to various types of minor and major emergencies such as breathing difficulties due to the water-filled

¹³⁷ Open eyelids appear as signs of waking up, only to shut again after a couple of seconds; a look can appear to be an attempt to make contact, only to stretch to the far-away horizon of an ongoing dream; an ongoing conversation is often interrupted by an uninvited hallucination.

12

Vid Pumpstopp som ej
kan hämtas med byte av
kontrollenhet.

ADRENALIN iv 10-20-40 µg Bolusdoser

LARMA ALLA JOURER + ev X-ops*

HEPARIN 7 ml (5000 E/ml) iv Bolus

FÖRBÄRED FÖR AKUT ÖPPNING

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

Figure 30: The provisional guidelines in case of a pump stop. The first line (underneath the three-line title) directs the reader to give the patient adrenaline intravenously. The second line says that all emergency duty staff ought to be called immediately. An additional call should be given to assigned experts – the footnote refers to names and direct phonenumber to those three experts: one heart surgeon, one anesthesiologist (who is also the author of this note), and one perfusionist. The third line directs the reader to give the patient anticoagulative drug Heparin, an anticoagulative drug, in order to prevent bloodclots. The fourth and last line says that the patient must be prepared for emergency surgery.

lungs, problems with arrhythmias, infections, critical blood counts, or overburdened kidneys and/or liver. There is also a continuous threat of high-risk emergencies such as sudden cardiac arrest or sudden pump failure. The rigid structure of post-operative care and treatment is ensured and maintained through daily repetition of standardized routines in order to prevent the occurrence of anything unexpected that might interrupt the ongoing course of things. However, the inherent unpredictability of the human body and technology render the whole process dangerous. If anything were to happen, the new set of standardized routines is designed to be enacted¹³⁸. The same pattern is identifiable throughout the whole post-operative care and treatment of this kind of patients. For instance, new provisional guidelines for proper action in case of pump failure are created by the chief doctors and distributed among the staff. One such example is a handwritten note that I found at the TICU next to a newly-operated HeartMate-patient's bed¹³⁹.

The patient's general state of being drugged and only partially awake makes it hard for doctors to take into account the patient's own subjective experience of his or her condition. With the exception of the patient's complaints about the pain¹⁴⁰, the doctors rely mostly on the technological tests, examinations, and clinical observations. However, the recovery that might be visible in various numbers and charts or clinical signs does not always concur with the way patients

¹³⁸ This was apparent in the episode of arrhythmia during the surgery described earlier (pp 269-270).

¹³⁹ At the same time, the staff at the Heart Failure Ward was being prepared for the arrival of mechanical help-heart patient through a crash-course type of *in situ* classes, which they complained provided no information about what they should do in case of emergency such as pump failure. One of the nurses complained about "a gap between TICU and the Heart Failure Ward that needs to be bridged" and wished for improved communication between the two units "mainly because it is a question of technical knowledge and routinizations but also to ensure continuity for the patients and avoiding too many different people working with this".

¹⁴⁰ Which are almost always met with an attempt to reduce the pain through increased level of painkillers.

experience their state, or as Bengt-Erik himself said on the sixth day after his operation: “The doctor says that I look better now... but I don’t feel that way”.

Born again

In the mean time, down at the Department of Cardiology, everybody asked me about how the patient is doing – most of them not referring to the patient by his or her name but simply as a ‘Heartmate’: “So, how’s our Heartmate doin’?”. People would ask about how the surgery went and how the patient is doing. Everybody at the ward seemed aware of the patient’s presence. This awareness was clearly a manifestation of the significance this kind of patient has for the people here.

These patients were different from other heart patients. They needed a special kind of attention and practical skills. When their implantations are completed they are given a necklace with a small engraved metal plate, saying “I have a Heartpump” (*Jag har en Hjärtpump*). Practically, this necklace is a safeguard ensuring that the patient does not receive any kind of medical attention that is considered wrong or even mortally dangerous for mechanical help-heart patients, such as for instance a defibrillation. It communicates the patient’s condition to other people in case he or she is unconscious or in any other way hindered from talking.

Nurse Vera talked about how difficult it can be for a nurse from a regular ward to take care of this kind of patients. Nurses usual daily routines are contested in encounters with these patient: “If something happens we can’t even take the blood pressure... and normally it’s the first thing we would do!”. Instead, the staff must rely on the patient’s own subjective experience – the routine practice of measuring the blood pressure is substituted, she said, with “How are you feeling?”. Although the special attention¹⁴¹ that HeartMate-patients received was partly grounded in the fact that their bodies were different from those of other patients (demanding different caring/curing and practical

¹⁴¹ For more details see Special treatment section below (pp 292).



Figure 31: The HeartMate-patient's necklace. Photograph by Haris Agic.

approach), there was something more to this. This attention was not merely practical but also clearly emotional. Most of the time people would ask about “our Heartmate” with cheerful smiles on their faces, displaying sincere caring attitudes, but also beaming forth an unmistakable mix of pride and awe. Clearly, everybody found what was now going on to be rather extraordinary, exciting, and even astonishing – not unlike the way people usually are around a new born child. Although clearly observable, these sensibilities were, however, rather subtle, expressed through language and gestures of awe and devotion – language and gestures which are also linked to the dominant biomedical and biotechnical discourse provided by the MIC and patient information material where the treatment is promised to give a “New Life” (see page 235). After all, Heartlands’ biggest asset, its strongest (and also most dangerous) weapon – a mechanical help-heart implantation treatment – has been used, enabling the staff to perform a sensational last-minute miracle of giving life to a dying man. “My life changed because I have my life back again” says

Anthony, an older man quoted on Thoratec Corporation's website¹⁴². Luetta, an elderly lady, praises the mechanical help-heart treatment that she had received, "Getting my pump was like being born again. I felt the difference between night and day. Suddenly I felt years younger. I felt like I could do anything"¹⁴³. In an article published in Mechanical Engineering's online magazine, Fred Zarinetchi, vice president of research and development at AbioMed¹⁴⁴, was quoted saying: "Bring their [the patients'] cardiac output to 8 liters per minute, and they're reborn." (Ehrenman 2003). A lung-transplanted patient said about her treatment: "Eight hours later I was reborn. I had received the gift of life. A second chance to visit the world" (TransplantBuddies 2012). Heartlands patients themselves talk about the treatment as the "new chance", and as something that is worthy of their gratitude.

Suspended kinship

Cecilia, Bengt-Erik's wife, told him on the seventh day after the surgery, during one of her visits, about the dog and cat back home. She told him that he had received quite a lot of mail but that she didn't bring it to the hospital. Cecilia also told him how she couldn't change the tires on their car by herself and had to ask friends for help. She told him about their outdoor furniture that she was going to take out this weekend – a task usually performed by Bengt-Erik. Then she remarked about how time goes by so fast: "Who would've thought... the time goes by so fast... weeks are just swooshing by!". Bengt-Erik looked at her without making any comments. I recalled what he told

¹⁴² URL: <http://www.thoratec.com/vad-trials-outcomes/patient-stories/details.aspx?sid=63>, date of access: 4th of January 2012.

¹⁴³ URL: <http://www.thoratec.com/vad-trials-outcomes/patient-stories/details.aspx?sid=46>, date of access: 4th of January 2012.

¹⁴⁴ "Abiomed® (NASDAQ: ABMD) is a pioneer and global leader in healthcare technology and innovation, focused on breaking new ground in **RECOVERING HEARTS AND SAVING LIVES**" (URL: <http://www.abiomed.com/about/about-abiomed/>, date of access 9th of February 2012, emphasis in original)

me earlier about time being so slow. Cecilia continued to initiate conversation: “Do you want me to get you anything?”

“No!” he responded.

Cecilia tried again: “If you have any ideas...”

“I’ll let you know!” he interrupted her.

“Because I thought”, she went on, “if you have any ideas now that the spring is coming ... since it is you who usually fixes things around the house...”

“I don’t, right now.” he responded again briefly.

“I understand”, Cecilia persisted, “but I thought that maybe you’d like to tell...”

“Can’t tell anything!” he said. Then Bengt-Erik started groaning and breathing heavily.

“Do you see something now?” Cecilia reacted. “Everything is upside down again” he said.

“Well you the ceiling is up there and the windows right there”, said Cecilia, pointing with her hand.

“Now it’s right!” he said but after just a couple of seconds started to hallucinate again: “Now the glass is upside down and the staff is crawling on the floor!”

“Am I on the floor as well?” Cecilia asked.

“Yes... now it’s good again” he said.

Eventually, a patient gets rid of the respirator and gains increasingly more control over his or her body. However, the recovery and more and longer hours of being awake, also bring: a) more boredom as patients generally experience time as slow, b) more space for frequent hallucinations where patients experience the unreal events taking place such as, “The room just turned upside down” or “The staff is crawling on the floor” or “I feel as if I’m lifting from the ground... flying”, and, above all, c) more frequent glimpses of the demands of life outside the hospital. Bengt-Erik had survived his surgery. Now life was calling him back. But the world outside was the world where time goes by fast – Bengt-Erik’s time could not yet keep that pace. The world outside was also the world where a spouse and

relatives ask questions, eager to integrate him into the ordinary course of things; a world with a house to be taken care of, mail to be read, tires to be changed, outdoor furniture to be taken in and out. This was a world for which Bengt-Erik was not ready. Not yet!

THE WARD

He must get up and get out and get some exercise... socialize with people... 'coz he's going home now... no more Mr Nice Guy... it's time to crack the whip... it'll do him no good to go around here...

CARDIOLOGIST AT HEART FAILURE WARD ABOUT A PATIENT WHO HAD JUST ARRIVED FROM TICU

The rehabilitation training starts with breathing exercises, regular toe wiggling until the patient is able to sit in a semi-recumbent position and eventually progress to sitting at the edge of the bed. The real progress is made when the patient is able to stand up after a couple of days. After being taken care of at TICU for a week or two, if everything is going as planned, a mechanical help-heart patient is transferred to a Heart Failure Ward for further care, treatment, recovery, and exercise, with discharge as the ultimate goal. What is required for this goal to be reached is that the patient is strong enough to be considered able to manage his new self at home. The mere act of transfer signals that the patient is considered to be in better shape and thus no longer a subject for the TICU kind of care. All the steps of the treatment – diagnosis, selection, preparation, operation, and post-operative care – are regarded as temporary passages, each of which should be passed through as fast as possible. Making it to the ward, thus, means that things are going well.

Even though the Heart Failure Ward might seem quite calm compared to the action-packed reality of TICU and ER, it is most often depicted by medical staff as the place of solid and demanding work – the place of action – the place where people deal with life and death on a daily basis. This is probably one of the main reasons behind the kind of status that human heart attains in this and other

hospitals. On the other hand, while death has its given place here, so does life. Thus, besides being a place of threatening death, Heartlands is also a place where sick hearts are mended and where lives are saved. This fact heightens the already high status that the human heart enjoys here. A tightrope walk between life and death is carved deep into the concept of the human heart. And it is done through daily practice here in Heartlands. Heartisans take much pride in their work. What is done here matters because it means the difference between life and death. Accordingly, the Heartisans are recognized among their fellow colleagues from other clinical areas as the ones who work with matters of life and death.

The concept of action as it is used among the Heartisans at the Heart Failure Ward refers to the process of doing, i.e. things that medical staff *do* in their daily work. The sentiment of this doing is further symbolically boosted by a turn of phrase that is commonly deployed in Heartlands. The emic term used most often to depict the eventful and dynamic nature of the Heartlands is in fact the English word *action*. It is often used in connection with Swedish idioms for happenings, i.e. events: *det händer grejer här*, *det är här det bander*, or *här var det action*. The closest idiom in English would probably be something like “this is where the action is”. The English word *action*, when used in a Swedish context, holds rather strong connotations of the kind of action that comes from the popular culture, especially the genre of action movies. It brings to mind images of military action, law enforcement action, extreme sports action, ER action, etc. The Swedish word *rejäll* is also used to describe the work here; this can be literally translated as “substantial”, “good”, “solid”, “proper”, “thorough”, or “hearty”, each translation holding, in given context, a strong connotation of ‘a whole lotta action’, ‘a lot to handle’, or ‘full tilt’. At the same time, during my field work in Heartlands, I was quite surprised at how calm the Heart Failure Ward in fact often is. There are, of course, things going on, but it is mostly the daily routinized course of action that takes place – the proper course of daily and

weekly rituals. This kind of habitual and scheduled action seems quite far from the action-movie kind of action that the expression suggests.

Of course, the level of action varies between different units and departments and also from day to day. For instance, the TICU is a unit where medical staff takes care of most severe cases before, after, and, at times, instead of operation. Here, the staff is always on alert, the technical equipment emits beeping sounds and blinks its lights. Here, the daily rites are combined with plenty of lateral thinking, creativity, and improvisation. The cardiothoracic Surgery Unite (CSU) is a unit where medical staff performs all the practices in a preordained manner but, on given occasions, they also need to deal with urgent and critical situations. In comparison, the Heart Failure Ward seems calm – it is usually neither as crowded nor as busy as TICU and CSU. A day at the Heart Failure Ward is for the most part made up of a familiar chain of clinical rituals. In fact, it wasn't until after the first six months of my field work that I got the chance for the very first time to witness a case of end-stage heart failure that called for implantation of a mechanical help-heart.

Organization of hope

Conventionalized clinical activities in Heartlands never stop. In fact, the total sum of practicalities might be regarded as a continuous process that is highly complex and consists of a myriad of formalized practices. These practices are usually rigorously structured, yet they also encompass spontaneous and semi-spontaneous elements. They are performed in never-ending repeating cycles, at even or uneven intervals or non-stop, day and night. In order to understand these practices it is necessary to see how the organization of their performance integrates participants into the ritual action.

These activities are highly habitual and form the pillar of Heartland society. The staff arrive at the scene on each shift already dressed in white scrubs (if they are part of the care-giving team, i.e. nurses and assistant nurses) and white coats (if they are part of the

curing team, i.e. doctors and medical students) with their name tags¹⁴⁵. Patients, on the other hand, are upon admission first undressed, dressed in a patient gown, deprived of their private property (which is put in a locker) and assigned the common designation (a room and bed number). The roles of all participants are strictly defined; everyone knows his or her place.

The rules of conduct are encoded into the way in which daily work is organized spatially and temporally. For instance, the spatial centeredness of a nurses' station as both the centrifugal and also centripetal core of daily work in the Heart Failure Ward symbolizes its actual importance for the work here. This is the place where all the patients come to get registered for hospitalization or to be discharged. This is also the place where doctors and nurses meet before hand-over talks or sitting rounds. This is the starting point of every work round. It is the monitoring room (Biotelemetry), gathering room, information center (a huge white bulletin board is hanging on the wall in the middle of the nurses' station displaying each room, each patient, and tasks to be done), and the administrative center.

As it is located one floor below TICU and Cardiothoracic and Vascular Surgery, which are located on the third and top floor of the Heartlands, the Heart Failure Ward is made symbolically inferior, reflecting the special powers of surgeons and anesthesiologists in relation to Heart Failure Ward people, thus symbolizing the Heartlands hierarchy (Adams and Schlich 2006). Temporal organization of the daily work is a highly complex mixture of: clock-time (time as given by a clock), schedule-time (time structured by established timetable templates), body-time (time as given by the human body, i.e. the time it takes for various physiological processes

¹⁴⁵ A name tag displays the professional title (doctor, aspirant, nurse, etc.) as well as the degree of expertise (Chief Cardiologist, Medical student, R.N.¹⁴⁵, M.D.¹⁴⁵, R.N., Research nurse, nursing assistant, etc.) and the department to which a person belongs, which also marks his or her area of expertise (Department of Cardiology, Department of Radiology, Department of Cardiothoracic and Vascular Surgery, Heart Intensive Care Unit, etc.).

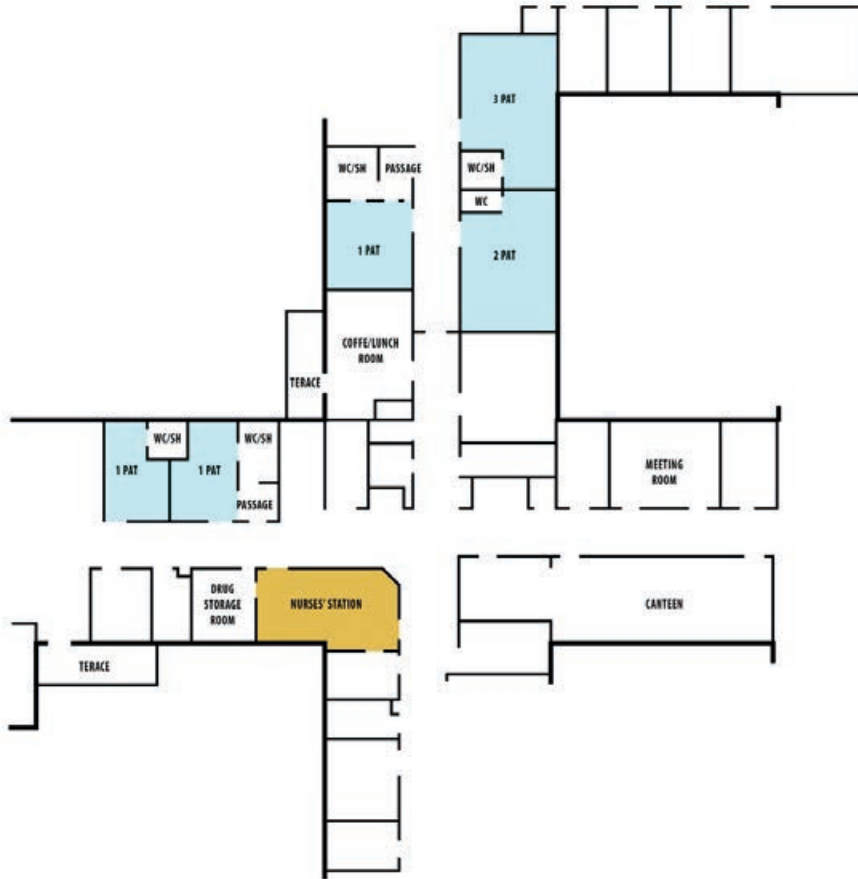


Figure 32: The Heart Failure Ward

to start, advance , end, and/or repeat – as for instance the heart rate). There is also action-time (time as given by action, i.e. the time it takes for various actions/practices/performances to start, advance , end, and/or repeat). The everyday work in Heartlands can be described as a continuous struggle to synchronize or relieve the tension between these different types of time. Curing and care-giving practices are strictly ordered in shifts and are structured according to established timetables. These schedules are structured in accordance to the given clock-time. The overall work at all times adjusts to the patient’s body-

time. Various practices start and end on different times and their duration varies depending on the ratio between all other types of time.

Routines of hope

Heart Failure Ward nurses execute doctors' orders. This involves jobs like measuring patients' blood pressure, sticking needles in patients' veins¹⁴⁶, taking blood samples and sending them to the lab, sticking patients' fingertips and measuring their blood sugar levels, and giving them their medicines. They also talk to patients, listen to them, inform them of what is going on regarding their treatment, inform

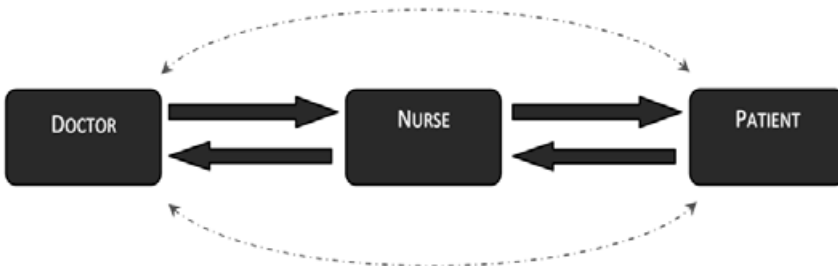


Figure 33: Flow of information

them of what the doctor has said and what examinations are on the agenda for the day or for the near future, and so on. Furthermore, they observe and they mediate. On the one hand, through their mediation they enforce the doctors' will – they instruct the patients on behalf of the instructing doctor. On the other hand, they also inform the doctors of all the symptoms, signals, and contextual details such as the patient's own desires and requests that might be of relevance. The doctors, then, are the ones who take into consideration the information received from nurses and make decisions for further action.

Doctors are also informed by reading patient journals and talking to other doctors. In addition, they engage in personal contact with

¹⁴⁶ A practice considered in particular as a mark of a skilled nurse.

patients during a couple of minutes of round work each day when they do swift and routinized physical examinations of the patients and, at times, take the opportunity to hear the patients' subjective descriptions of their situations. However, the main source of information is detailed reports from nurses. These reports provide the doctors with crucial evidence on which to base their opinions and make further decisions about how to proceed. After the decision is reached the doctor instructs the nurses and apprentice doctors on what to do and how to do it.

The ones spending even more time with the patients than the nurses are assistant nurses. They serve food to patients, help them dress, undress, clean up, brush their teeth, take a shower, go to the toilet, or they bring a bedpan to them. They fix their sheets and pillows, close and open the curtains, prepare special things to eat or drink to put a smile of pleasant surprise on the patients' faces. They also carry patients' messages to the head nurses and doctors and take them to various examinations and are usually the first ones to respond to their calls. Their role as mediators between patients and nurses resemble the nurses' role as mediators between patients and doctors. Although these two patterns of information flow differ in some qualitative aspects – such as the kind of information exchanged, the duration of interaction among the involved actors, and the level of interaction – they are identical in their structure.

Special treatment

Mechanical help-heart patients receive a different kind of attention than the rest of the heart patients at the ward. These patients embody the state-of-the-art treatment at the Heartlands and are in such a poor and uncertain condition that they are granted the best single rooms in Heartlands and also the unreserved attention of the staff. They are also a subject of many formal and informal conversations, anecdotes, and jokes, and are a target of everyone's attention. Their presence in the ward is often discussed and upon their arrival all cardiologists – including those who are in no way included in their treatment – are

CHECKLISTA HEARTMATEPATIENT							
Datum							
Blodtryck fm							
Blodtryck em							
Temp fm							
Temp em							
Saturation fm							
Saturation em							
Vikt x 1							
Kalorimätning							
M. Calogen 30 ml							
M. Calogen 30 ml							
M. Calogen 30 ml							
H-M avläsning fm							
H-M avläsning em							
H-M slangreng. fm							
H-M slangreng.em							
Rengörs med klorhexidinlösning							
Oml.drivlina var 3:e dag med Duoderm							
Filterbyte 1g/mån							
Självtest av kontroll- enhet 1g/v							
Blodprover blodstatus, Na,K, Krea, urea leverstat må, ons och fre							
Vancokonc.v.a.d							
CVK-oml							
Dusch							
Avföring							

Figure 34: Checklist for mechanical help-heart patients.

overtly notified at one of the twice-weekly morning meetings. These morning meetings are also used to continuously update the cardiologists about the way things are progressing with the mechanical help-heart patient. No other patient is given this much attention. With the arrival of a mechanical help-heart patient a completely new level of excitement is worked up among the Heartisans – clearly visible as most of them are really excited about it. This is accompanied by frequent visits from the people from TICU and Cardiothoracic Surgery, indicating that there is something rather ‘exotic’ taking place here.

None of this means, however, that other heart patients are neglected due to the arrival of a HeartMate-patient nor that they are given better treatment and care. Heartisans themselves would say that everybody is given the best care that Heartlands can provide, and there is no reason to doubt this. The fact is that this particular treatment is significantly more challenging and demanding in comparison to other treatments. Mechanical help-heart patients are brittle and complex, their pulses cannot be measured, they are especially sensitive to infections, their lives depend on a machine, there are batteries that need to be charged and recharged and also a vast number of other things that can go wrong. To make sure that all these musts are attended to regularly, Heartisans have made a checklist especially designed to suit the practical requirements of mechanical help-heart treatment (See Figure 34). This sheet of paper is used each day by nurses and assistant nurses to guide their work with the patient. Blood pressure, body temperature, and oxygen saturation must be measured twice a day, morning and afternoon. The patient must be weighed every day, and his or her daily intake of extra calories is monitored, measured, and controlled. The working of the mechanical help-heart is monitored twice a day, the driveline and the driveline exit hole are cleaned with chlorhexidine solution twice a day to prevent infections, and the driveline is dressed every three days. The filter needs to be changed every month, the mechanical help-heart’s control unit must be self-tested once a week, and blood tests

are to be performed every Monday, Wednesday, and Friday. If the patient has a central venous catheter, it should be checked, cleaned, and dressed regularly. Showers and bowel movements must be reported.

Daily schedule

A sheet of paper hanging on the wall in nurses' station lists all the things that dayshift nurses are required to do.

Nurses, dayshift:

- | | |
|-----------|--|
| 06.45 | Hand-over talk, visits to the patients, distribution of the medicines, check-ups, collecting the blood-samples, renewing the infusions, informing the patients about the examinations planned for today. |
| 07.45 | Sitting round at doctors' office, check the lab results and sign together with the doctor in LabRos |
| Morning | Ward round, round work. Going through the schedule for today together with the work-team, round work is distributed. Fill up the drug-cart, prepare for patients' release, welcome new patients from the waiting list. |
| Afternoon | Biotelemetry data log hand-over talk, writing of the morning report. Distribution of the medicines, check with the evening-shift nurses. NOTE! Check the round work checklist and make sure it matches. |

These assignments are the scheduled routinized musts and make the core of the daily job of care giving in Heart Failure Ward¹⁴⁷. For this

¹⁴⁷ This particular list is most probably not so unique for Heartlands nurses. Other medical wards in the hospital have at least similar kinds of schedule and quite comparable types of chores. The only thing on this list that might be regarded as characteristic for the Heartlands is probably the reading and reporting of the Biotelemetry monitoring. This kind of technology for

reason they are summed up, ordered in a timetable template and put on display in nurses' station. Each task is to become embodied through repetitive daily practices and, apparently, also through distribution of symbols – the paper sheet found hanging on the wall inside the nurses' station being one of such symbols. Besides functioning as a reminder to help nurses keep track of those daily tasks that are considered most important, this sheet of paper works as a coercive reminder of the obligations that come with being a heart failure nurse – hallmarks of the nursing profession. The fact that it has been printed out and hung up on the wall in the central and most crowded room in the Heart Failure Ward proclaims not only the undisputed quality of these responsibilities but also infuses the Panopticon-like feeling of being watched. It is a reminder, an instruction, and an order.

Constructing significance

Each of the listed tasks is in practice composed of several smaller practicalities. For instance, the actors participating in hand-over talks are the nurses whose work-shift is ending and the nurses and doctors whose work shift has begun. Here, the former group informs the latter in customary fashion about each patient in the ward, the ones who have been discharged and the ones who are about to arrive. It is usually the head nurse who does the informing while others listen, take notes, and ask questions. Each patient is portrayed with reference to his/her name, room number, sex, age, day and method of arrival, diagnosis, condition at arrival, treatment being used, response to that treatment, current condition, plans for further treatment, and estimated hospitalization time.

Prior to this task, the doctors and some of the nurses whose shift has begun had, if things were done properly, already completed another related practice – reading from the patient's digital file. It

surveillance of patients' heart rhythm is typical for all types of cardiac care units.

should be noted, however, that the reading of patients' journals before hand-over talks is not a strict requirement and applies less to nurses than it does to doctors. This practice is anthropologically fascinating as it is not performed collectively but individually – the individual doctor goes into a room, opens up the computer files of all the patient's hospitalized during their shift and reads. Sometimes, a nurse might do the same. In a sense, the performance of this rite is done in private, out of others' sight. Yet it still becomes visible for others during the subsequent collective hand-over talk (which always takes place almost immediately after the individual reading). And here, it also becomes evident whether the preceding practice was done properly or not. The participants are supposed to share their knowledge gained from the digital information. Failing to do so reveals that the preceding practice was performed poorly – or not at all – and that the person is unprepared. However, the hand-over talk rite is designed to alleviate the negative effects of such – possibly poor – preparations that may occur. The nurses going off duty are responsible for reporting on the general condition of each patient, and thus everybody gets informed regardless of whether they have thoroughly read the patient's digitalized files or not. The difference is that in the latter case they are not able to detect any eventual faults in the oral report provided but must instead just trust in what is being said or, perhaps, check the validity of gained information after the hand-over talk is done.

The particulars of each individual patient are highlighted during the hand-over talk rite with the aim of providing a coherent picture of the way things have developed during the entire shift; this is a process to inform the staff about all the tests and examinations that are planned, etc. Every little thing may be of huge significance and should, thus, not be left out. At times, when regarded as indispensable, the patient's entire illness history is also described. This was exemplified in Nurse Anna's informing her colleagues about Bengt-Erik, providing a chronology of events: "... mechanical aortic valve in ninety six... a CRT [Cardiac Resynchronization Therapy]

with defibrillator in two thousand and six... getting worse and worse ever since last summer... can't walk thirty meters... has been hospitalized several times at the K hospital for treatment with Simdax". The hand-over talk rite is based on detailed description. The 'detailed' here refers to a formalized list of facts that are regarded as essential:

1. Reason for seeking medical help
2. Main diagnosis
3. Underlying diagnosis
4. Other diseases
5. Health history – medical *epicrisis*
6. Details of treatment provided so far
7. Patient's response to provided treatment
8. Details of further treatment
9. Drug allergies
10. Test results
11. Pulse rate/ biotelemetry report
12. Respiratory signs
13. Blood test
14. Blood pressure
15. Fluid balance recording
16. Nutrition
17. Elimination (bowel movements)
18. Activity
19. Sleep
20. Psychosocial status
21. Social background

A highly thematic structure of information exchange such as the one presented here is, of course, not solely a property of hand-over talks. It is, in fact, the very fundament of most other kinds of ritualized "rounds" and other forms of information exchange in Heartlands. These themes provide a guiding template in all logs, journals, or records. Analogous or slightly modified thematic blueprints are to be

found in all patient journals, examinations logs, surgery logs, letters of referral, and notes. Moreover, they structure even the more informal method of information exchange. For instance, two days later, during a routine morning round, the same nurse as in the example above informed the attending doctor about the same patient. This time, the informing was done swiftly, in the corridor, prior to entering the patient's room. She said that the patient was planned for ultra-sound examination of the central venous catheter attached to his neck: "... but he has been urinating well... Doctor Claes [arrhythmia cardiologist] was here to adjust his pacemaker... Furix treatment was terminated ... his blood pressure is better now because of that...".

The reports such as this one are quite impressive as they are often remembered and told without notes. The content of reports, their thickness, may vary during these less strict forms. What is brought up is subject to a nurse's judgment (apart from the required account of clinical signs and symptoms that are directly related to the patient's illness) regarding what counts as important information. For instance, during one of the sitting rounds early in the morning, Nurse Lina took the opportunity to alert Doctor Arvid about Fredrik and about the itch that he's been having all over the body. "He suffers from it, he certainly does! It might be some kind of allergy. He is scratching himself raw", she said, wondering whether there are any medications they can offer him. Doctor Arvid said that he was going to look into it, but that he, at the same time, was more concerned about how to get him back in shape again: "If he is to be transplanted then he must be strong enough to be able to cope with such a serious operation".

Here, the nurse informed the doctor about the itch that the patient has been complaining about. From her perspective, it was a detail significant enough not to be left undisclosed and undiscussed. At first, the doctor acknowledged her concern but made a sudden turn by degrading the importance of the itch in comparison to other aspects of the patient's condition that need to be prioritized, thus constructing the order of significance among the facts. In spite of the

liberty of individual actors to provide additional information which is not required by regulatory thematic form, as in this example, the form itself is still adhered to carefully. It is if an actor should leave out an important piece of information that risk of harm is brought upon the patient.

The thematic form that organizes the content of information flow works as a safeguard against the threat implied by overlooked facts. It is not merely a matter of every little detail being of potentially crucial significance – a lost piece of information might indeed have a deadly outcome. The stakes are high here in Heartlands, and the higher they get, the harder the fall. The standardization of practices provides a way of dealing with this hazard. Ritualized action provides rules of conduct. These rules are prescribed by guidelines, policies, and general discourse and are continuously inscribed into the performed structure of each practice. To forget to mention some of the themes that are regarded as crucial is considered a breach of these rules. Failure to conform means taking on the burden of responsibility for anything that might go wrong from then on, which can be connected to the lost piece of information as the very cause of the error. When things go wrong in Heartlands, and sometimes they do, a search for possible lost information and its cause is very likely to be initiated. The causes of errors of this kind might be: 1) technical, 2) organizational, and 3) individual. The first two are the most common targets of blame. An individual, on the other hand, might be held responsible for a breach of professional conduct that has either caused a minor disturbance in the treatment process with no severe damage to the patient, or a larger threat that could easily be avoided. The errors causing minimal or no harm to the patient are usually not formally reported nor revealed for general discussion. Such cases are usually settled on the spot by brief discussion among the actors involved; a doctor might, for instance, raise his or her voice and display discontent while scolding the nurse for failing to provide some key facts. More serious errors – for example a life-threatening complication, a death or a serious permanent injury – are, according

to my data, always reported. However, they are usually not ascribed to a single individual due to the gravity of such accusation. All the empirical evidence gathered during my fieldwork in Heartlands suggests that individuals are rarely, if ever, blamed for serious errors¹⁴⁸.

In any case, the thematic grid is continuously applied through the performance of daily ritualized practices as a way of ensuring a reasonable level of patient safety. Its function is to minimize the likelihood medical errors occurring. There is also something else, by no means less significant, that is communicated through these thematic forms. As the key function of thematic form is to ensure the constant supply of indispensable facts, it can be argued that the underlying Heartisan views, ideas, and values are principally assembled around the concept of evidence (*evidens*). Hence, the way these practices are organized reveals a total reverence for evidence among Heartisans. It reveals the large chunks of interpretational logic for attribution of the meaning underpinning the biomedical ways of thinking. Evidence is the omnipotent synthesis of medical science and medical practice. In medical science evidence is secured mainly through clinical research – preferably randomized controlled clinical trials. In medical practice, on the other hand, evidence is secured through ritualized worship of clinical facts and guidelines based on the synthesis between previous research results and observable clinical signs at hand. Evidence-based medicine is a concept that is of indisputable and supreme significance for Heartisans. This implies four things: 1) the world is made up of facts, 2) the facts are observable and measurable, 3) the facts are to be observed and measured either in real time while practicing medicine (for instance taking blood pressure or conducting physical examination) or through the complex research apparatus of medical science (for instance randomized controlled clinical trials), and 4) any kind of medical practice must always stand on the shoulders of medical science with

¹⁴⁸ Unless, of course, the error might, beyond all doubt, be a result of ill intention. No such accusation occurred during my time in Heartlands.

one foot and on the constant stream of observable clinical facts with the other. The meaning attributed to medical practice is made in and through interpretational logic evident in the detailed accounts of the ways daily practices are organized. A continuous demand for facts, inscribed in the formalized thematic blueprint of clinical information-exchange rituals, legitimize and consolidate the key quality of evidence as indispensable. The facts of which the evidence is made up constitute the core element in Heartisan logic. Compliance to the facts and evidence is the Heartisans' principal cultural value. Ritualized, formalized practices are their means of doing this – their *modus operandi*. Constituting a means to an end is not the only function of these ritualized practices. They provide: 1) a forum where groups of participants can assemble and thus reinforce the sense of community, 2) the organization of performance through which the same participants can be integrated and thus provide the safety of continuity, and 3) a practical space where groups' core values are continuously being displayed and enacted and hence also negotiated and reinforced thus preserving and modifying their shared understanding. What's more, by just being put in action, these values determine the mode of action and are legitimized through that action. The rigidity of ritual organization implies professional accountability – the key ingredient of helping the patients gain their sense of hope.

Ultimately, the list of facts that are continuously being demanded through these formalized practices also gives away what kind of facts are regarded as valuable and important. Naturally, not all facts can be taken into account because the world of facts is inexhaustible – the trick is in picking the right ones. Therefore the thematic templates are structured as a way of ordering the facts according to their significance. In Heartlands, the right facts are displayed in daily rituals where information is exchanged among the actors, in checklists and schedules, in the thematic structure of information exchange, in the thematic structure of meeting agendas and in the topics that are discussed every day. Certain types of facts are sought because they are considered to be significant and relevant to medical knowledge and

practice. At the same time, selecting the right facts means ignoring the insignificant ones. As the logical inference in arguments that guide clinical practice builds on premises that are made of carefully selected facts, it is bound to arrive at certain types of conclusions, qualitatively very different from any conclusions inferred from differently selected facts. What is regarded as significant is inscribed in the quality of selected facts. This implies that the clinical perspective, on which clinical practice is based, is fundamentally selective. The more selective the perspective, however, the more limited the horizon and the action-space for those involved.

On one occasion, in the lunch room at the Heart Failure Ward during the lunch hour, Doctor Jessica complained to Nurse Molly, Physiotherapist Lea, and me about the lack of rules for managing the patients who are down and disheartened and who might be “in need of some kind of conversational therapy or something”. When I asked her if there are any kinds of official guidelines regarding this issue that doctors here in Heartlands act by, or if this is a matter of each doctor’s personal preference for how he or she chooses to handle this, she answered: “It might even be the case that they’re not handling it at all!”.

Clearly, less measurable sides of a patient’s condition seem to fall outside the web of clinical significance. Doctor Jessica’s concern was an observable phenomenon in Heartlands. The patients who proved incapable of managing their emotions would, according to Heartisan standards, be regarded as tricky or hard to handle. Often, cardiologists would remind such patients that they, as heart doctors, are experts in heart-related matters and therefore cannot help them deal with other problems.

There were times when a cardiologist would go as far as to label an explicitly unhappy patient as depressed – a specific type of clinical diagnosis that is a professional property of psychiatry and not of cardiology. At time like this, a cardiology doctor would call in psychiatrists to come and take care of things, as though to confirm his or her assumptions. For instance, one of the patients had been

complaining about fear and anxiety, and had been quite demanding for the staff at Heart Failure Ward. A chief doctor in charge, Doctor Arvid, had ordered a consultation with a psychiatrist. However, psychiatrists concluded that there was nothing wrong with the patient – a conclusion that had made Doctor Arvid quite snappish: “Okay then, they must refer to whoever will take responsibility for the mentally retarded... we take care of heart-related matters... so ring them [talking to a nurse] and say that... good... we understand, but we’re not buying it!”.

Apparently, the composition of significant facts selection provides a structure for the clinical practice which, due to its categorizing nature, is fundamentally normative. At the same time, it also creates a specific kind of normativity to which a patient is continuously subjected. In the mist of the uncertainty and fragility of their condition, mechanical help-heart patients seem to embrace this clinical grid of significance as a compass and map for navigating their way out of the ambiguity. The knowledge-based norms are thus treated as a foundation of hope. This becomes particularly evident in patients’ shunning any deeper scrutiny of their own emotional states or in their disinclination to discuss their futures in any greater details. For instance, when I attempted to encourage Bengt-Erik to talk about his future, he responded briefly, “I have [a mechanical help-heart] now and I don’t know when the transplantation will be, so it’s hard to plan beyond that ... right now I just wanna be as strong as possible before the transplantation ... of course, I think about the time after transplantation ... aiming for total recovery, getting back to normal, except for the fact that I will have to eat a load of medications for the rest of my life... I don’t wanna be hospitalized forever, I wanna do things”.

Clearly more aware of his current situation than of his future, Bengt-Erik echoes the meaning that was already given to him through various practices of informing. Remember, for instance, doctor Arvid’s assertion that the point of mechanical help-heart treatment is to “get stronger, build up some muscles and get in the best shape

possible in order to get through such tough operation as heart transplantation”. Although Bengt-Erik does mention his future as “the time after transplantation”, he speaks in rather vague terms of “total recovery” and of “getting back to normal” – both of which seem to express a nostalgic sentiment more than a wish to break new grounds in his life narrative. On another occasion I asked him about the waiting list for a new heart. He said: “All I know is that I’m not on a waiting list yet... so I have not started waiting yet”.

When asked how they are doing and how they are feeling about the whole thing, most mechanical help-heart patients would, at the time they are still being treated with their mechanical help-hearts, usually respond with a brief “fairly well”, “better”, “okay”, “not so good”, “tired”, “sleepy”, or “worse”. If further encouraged to explain this they would usually recite the clinical information that doctors and nurses continuously gave them, for example “I saturate better”; or “My blood pressure is back to normal”. Very rarely, if at all, did they refer to their emotional states. This seemed to be a part of their life that was systematically ignored – mirroring the formalized ways according to which these clinical practices are structured and performed – as if it was somehow insignificant or, even worse, dangerous. The sitting round helps staff focus on each individual case and customize the work to be done in harmony with the course of planned treatment. It takes at least one doctor and one nurse for a sitting round to be performed. Ideally, however, it is performed by the attending doctor, aspirant doctor, head nurse and another nurse. It almost always takes place in one of doctor’s offices – a small room measuring approximately 2m x 3m and furnished with one patient/examination bed that takes up almost all the space, one little table equipped with a computer at the far end of the room beneath the window, one office chair at the computer, and one wooden chair against the wall to the right. The doctor would usually sit at the computer, like a boat captain taking charge of the steering wheel, or he/she would act as navigator and let the aspirant doctor handle the

Avd 7, Svikt	Dagens datum	Kom ihåg! ▼
18 [redacted] -17 Hkr 14/1 tungt CBS m/ neg brady P-kross digoxin & inthone 15/1 vandat även bevarat f.l.	APD dos 21/1	23/1 ^{Hösten} VPL 13 ⁰⁰ B-gt OHLK 17/1 Tilt fure + 20/1 Pnevmoni / aubh 135cc 19/1, 90 21/1, 43
14/1 Hg pulm lättas fure 15/1 brady 85 & b/ir f bgt CBS helogen Isoprenalol m/ neg f.H. Hefablaide 22/1 Zoroxolyn 20/1 Hg rygga kompressionsstrålen H. hasbeldi d. 2 x 2 sturr bristat f.H.	fall	Med blennit progredient pänt med 80 Dexfen → Muddie Kompressen <u>Dusik</u> Injekt veg bgt x1
19 [redacted] -20 H. m/ir med Omt + Avb H 15/1 pm DDD Öst mält b/ir 15 C. 1, 738 Herpes herpes osse 15/1 Hg ur Tavegyl.	hasbeldi d. 2 x 2	Muddie K16 SR 70-90 An 16 + 19 13 ¹⁵ 16 ¹⁵
dement Mskellen Pz. j. 1. 05 + Omt auni 35:1 [redacted] -35 21/1 CBS m/ir ettelt 45 min falg t.H. skatag. Soloken smältfri Öst rassol Öst 16 H. n/ir 2 Trimbgt telodipin metoprolol FPL → Soloken - ST ↓ m/ir → SK 102 HT A-pm 04? [redacted] -46	20/1 Avk	Muddie K16 SR 70-90 An 16 + 19 13 ¹⁵ 16 ¹⁵
21/1 corai Hkr 20/1 CBS f b/ir uppl Heflapping Metoprolol m/ir neg ST ur CBS Planie 838 Heflapping Metoprolol	Metoprolol	Metoprolol

Figure 35: Nurse checklist

computer. The head nurse would usually bring with her the round work cart with patient files and mobile computer station as an aid in following the details of the doctor's searching through the patients' files. The nurses are also armed with a sheet of paper specially structured to fill in the most important facts they must not neglect

about each patient as well as the particular parts of the treatment that are planned for the day (Figure 35). The left column notes the room number and/or bed number, the patient's name (hidden here for confidentiality), and age. Under this, the nurse notes the particular patient's diagnosis, other diseases, the medications, treatment forms, and examinations done, ongoing, and planned, and various test figures. The right column is headed *Kom ihåg!* meaning "Remember!"

Each patient's digital file is opened during the sitting round rite. The list of facts that is checked and discussed resembles the one in hand-over talk rites (pp 298) with one significant difference – it is mainly during these sitting round rites that doctors make changes in medication and treatment and other needed adjustments with reference to the patient's response to treatment provided thus far. It is not only the steering of this rite that is done from here – this route planner also decides the course of further treatment of all eight patients at the Heart Failure Ward. This is where the doctor makes the vital decisions and designs custom-made treatment plans for the patients.

Round work

After the morning sitting round, doctors start the round, followed by an entourage of people dressed in white. The head nurse is the first one following the doctors, pushing the cart with patient files, mobile computer station, medicines, and various paraphernalia. This cart is one of the most important tools in the nurses' work. She is followed by a second nurse, an assistant nurse, and often also a couple of nursing and medical students. During the round work the medical staff visits all the patients in each room of the ward.

The round work consists of three phases:

1. Anamnesis – doctors encourage, when possible, patients to tell their subjective experiences of their condition and to describe their symptoms.
2. Physical examination – doctors go through the customary steps of physical examination.

3. Conclusion and information – doctors state their opinions and inform the patients.

The attending doctor starts by knocking on a door whereby he/she enters the room, expresses his or her greetings as a mark of courtesy, turns to the plastic container hanging on the wall next to the doorframe in each room, squirts his/her hands generously with alcohol-based hand rub and approaches the patient (or the first patient if it is not a single room). The ritual of alcohol hand cleaning is then repeated by each and every member of the following cortege. The doctor initiates conversation with the patient in question, usually by asking how the patient feels, how she/he has slept, if his/her appetite is satisfactory, and so on. Then the doctor, either alone or joined by the aspiring novice, initiates the routine physical examination. The regular examination consists of listening to the patient's heart and lungs with a stethoscope, exerting pressure on the abdomen, tapping the patient's back, and feeling the patient's legs. During the examination the doctor might ask the nurse about some specific information such as the lab results, the blood pressure, or the fluid balance. After a short while the doctor shares his/her professional opinion with the patient and informs him/her about the situation at hand and also about the further treatment. The encounter is rounded off with another set of greetings. Turning away from the patient, the doctor turns to another plastic container with alcohol-based hand rub placed strategically on the footboard of the bed and squirts a generous amount of sterilizing liquid into his/her palms rubbing them vigorously. Then the doctor moves on to another patient or, in the case of a single room, heads towards the door. When exiting the room the doctor and the entire posse stop at the door frame to once again use the antiseptic hand rub.

Heart myths

While lying in his or her bed, in his or her room, the patient is regularly discussed elsewhere, during meetings such as the sitting round, morning meetings, and hand-over talks, and also unofficially, yet not necessarily less routinized, during lunch and coffee breaks, and in the corridors. The formal meetings and talks are conducted according to the step-by-step routinized custom where the doctors acquire information about the patient, primarily from their colleagues, attending nurses, journal notes, and monitoring drafts. Then, based on this information, they make decisions on the further treatment. The other, less official ones, however, are a custom not only typical of Heartlands, but of Swedish culture in general. It is practiced in Heartlands, revealing among certain groups of Heartisans the particularities of their culture in a manner common to the vast majority of inhabitants of Sweden, thus enacting wider cultural meaning into a particular set of specific (medical) practices.

Stories are told all the time among the medical staff in Heartlands. These rituals of storytelling are practiced mostly during the *fika* and lunch breaks, or during the calm moments when most of the patients are asleep and the ward seems to operate on autopilot. At times, they are also told in the nurses' station, during the rounds, in the corridors, etc. The coffee break, called *fika*, is a typical Swedish custom when the coffee (or tea) drinking is often accompanied with a piece of pastry, a cake, a cookie, or a slice of bread with some butter and cheese. It is a culturally specific manifestation of a rather universal human phenomenon of social gathering with strong symbolic value. In that sense, it is similar to the Japanese tea ritual (Anderson 1987; Kondo 1985), the Siberian tea ritual (Pesmen 1995), the social significance of mint tea rituals in Morocco (Sudakov 2005), Turkish coffee (Kucukkömurler and Özgen 2009), the cultural significance of Bosnian 'coffee-visits' and ceremonial drinking of *šerbe*¹⁴⁹ (Bringa 1995), and the symbolical importance of coffee throughout the world (Sherry 1995).

¹⁴⁹ Sweetened and flavored water.

Fika has quite a strong connotation of a social gathering, which allows a temporary escape from other daily activities. It provides the opportunity for informal discussions or simply meditative moments of relaxation (Lee 2001), and is thus regarded as a ritual with more value attached to it than merely a coffee break. In fact, *fika* is so deeply rooted in Swedish culture that it has spread from its original setting, i.e. the intimacy of home, to becoming a part of nearly every work place in Sweden¹⁵⁰.

Lunch is another daily ritual (for day shift) where people gather in a less official way¹⁵¹. It is similar to *fika* – a time to chat, reflect, relax, discuss, and tell stories – all in a casual manner. The topics are many and combine themes from work and private life in a spontaneous and lively mixture. In a sense, *fika* and lunch provide the opportunity to break free from daily routines and pay attention to those aspects of human ties so central to the practice of health care, which cannot fit within the work-related practices.

With the appearance of a HeartMate-patient, the storytelling grew immensely. Although many stories often revolved around work-related issues they nevertheless made room for those sides of

¹⁵⁰ The most common model is that it takes place twice during one shift; for the day shift, this means once before noon and once after. Each *fika* usually lasts for twenty minutes – a time that is a part of regular working time and is paid for. This is even legislated through Restriction of Working Hours Act where it is stated that each worker is allowed to take a shorter break from work when possible. The duration of the break is counted as five minutes per worked hour. In a regular eight-hour day this amounts to exactly forty minutes – sufficient for two proper *fikas*.

¹⁵¹ One can either stay at the ward and eat in a coffee/lunch room, or go to the hospital canteen or some of the restaurants nearby and eat there. Usually, people don't swing between the two but are rather loyal to their routines – either they bring their own lunch-box and have their lunch in the coffee room or they are a regulars at the hospital restaurant. It is quite common that the lunch-boxes are bought at the hospital restaurant but consumed in the coffee/lunch room. There are times, of course, when individual and/or smaller groups break free from their routines and do the opposite. To leave the hospital entirely and go to one of the restaurants nearby is considered a treat and is practiced by some – randomly or regularly – usually during the week following payday.

participants' occupations that are habitually marginalized from their daily practices through a mixture of culturally specific tales. These concern behaviors, extreme risk situations, professional hardships and skills at dealing with knotty situations, "difficult" patients, medical successes, mishaps, power-plays, institutional and organizational strains, human suffering, joy and despair. The stories are told individually and, even more often, collectively. They range from personal or shared anecdotes chronicling past events to more distant friend-of-a-friend tales spread by word of mouth.

One thing that nearly all these stories have in common is the fact that they revolve around the human heart – sick hearts, medical practices of mending sick hearts, heart technology, people suffering from sick hearts, and so on. Thus, I call them "heart myths". They are traditional stories accepted as history and stories that embody Heartlands' specific beliefs regarding human hearts, heart technology, and heart-related medical practices – in short, Heartlands folklore. The very idea of Heartlands as a place of *action* is kept alive by these stories. During the mechanical help-heart treatment things are done in a more tangible way as a part of the team effort in which particular people with specific problems are attended to, and where the particular challenges of particular situations are confronted and managed, where the routine of habit created by formalized and standardized social practices (ritualization) redefines problematic situations and thus brings the sense of empowerment. But the heart myths are all-encompassing, they speak of all heart patients by speaking of one, they speak of Heartisan people and the joy and hardships of their daily lives, they are told in terms of dos, don'ts and oughts, they are suspended in the web of standard ideals which they themselves at the same time spin further with symbolical romanticizing and demonizing details. Heart myths help organize and make sense of the heartfelt impressions absorbed during the treatment practices by adding social, cultural, and often emotional aspects to them.

The noticeable change in both intensity and frequency of these rituals brought by the appearance of a HeartMate-patient – a patient who is characteristically extremely brittle with a treatment that is characteristically extremely risky and challenging – is the very first indicator of how significant these heart myth rituals are for medical staff. During one of the lunch breaks in Heartlands, three more experienced nurses expressed their awareness regarding the pressure that rapid development of medical technology combined with low incidence of HeartMate-patients in Heartlands brings to bear on their work. They also talked about phenomenology, statistics... and about HeartMate-patients¹⁵². One of the nurses said that HeartMate-patients are quick to learn how to manage their new gear – the mechanical help-hearts together with the accompanying control and monitoring systems. At the same time, she complained about the fact that the time periods that pass between the mechanical help-heart treatments¹⁵³ cause the nursing staff to forget how it all works, and they are puzzled when patients turn out to know these things better than they do. All the mechanical help-heart patients that had the first version of HeartMate® are dead now, they said. They also told me about how big and clumsy this first model was, with a huge cart and a handle that had to be turned manually by the nurse in order to get the pump started when it got jammed. Thus, they never could leave the patient on his/her own. One of the nurses went to a patient's home and there were times when nurses would sleep over at the patient's home. These days, they said, nursing care is not needed as much because patients in principle have better knowledge of managing their machines than the nurses do. At the same time they expressed empathy about how hard it is to live with a mechanical help-heart: "...it must be so hard! I would just lie down and put my head under the pillow [*jag skulle dra filten över huvudet*]", said one of the nurses with

¹⁵² Mechanical help-heart patients – are called "HeartMate-patients" in Heartlands because of this particular brand of mechanical help-heart being the one in use in this particular hospital.

¹⁵³ Approximately, Heartlands does 1-3 mechanical help-heart treatments a year.

a gesture of dread and resignation. Yet the other one pointed out that "... we humans don't do that because we are amazing and have the will to fight inherent in us". Then, one of them started talking about Niklas, a former HeartMate-patient, who had survived both the implantation of a mechanical help-heart and the subsequent heart transplantation. She recalled that Niklas didn't want to get a heart transplant but wanted to go with his mechanical heart for as long as possible. The other nurse filled in that he was probably thinking that things will get more complicated with yet another surgery and then also with all the immunosuppressants and medications and everything. This story was an example of personal doubt that these patients tend to display about the future. What struck me funny was that it seemed as if the nursing staff members have not forgotten about their mechanical help-heart patients. They remember! They remember Emelie, Niklas, Jan-Håkan, Torbjörn. They remember! And they tell stories about them.

During another lunch break, Physiotherapist Lea told me a story about a HeartMate-patient, Nathalie, who enjoyed extra attention from the medical staff and also from people in general. "They become something like stars", she said. Lea was convinced that HeartMate-patients easily build their identities on their mechanical help-hearts as it gives them all the care and attention, recognition, and sympathy. She also recalled Niklas, a patient who didn't want to get the heart transplant that he was waiting for because "he got on well with his HeartMate[®]". "As soon as they get transplanted", she said, "they also lose all that attention they have been receiving during their time with HeartMate®. This usually results in their feeling low-spirited, even depressed, and feeling abandoned and alone".

After a while, Doctor Jakob and Nurse Anna joined us and Lea told us another story that she had heard about a HeartMate-patient who had been victim of a robbery. Reportedly a bag snatcher had tried to steal the bag containing the control unit and power supply equipment mistaking it for a regular bag with valuables, pulling the power cord which he didn't know was attached to the heart. "It must

have hurt horribly, I can imagine” Lea said to everybody’s awe and unreserved interest and continued with another story about a HeartMate-patient playing with a young child who accidentally grabbed the power cord and pulled it so it came off. The story about the HeartMate-patient Nathalie, was taken from Lea’s personal experience. There are plenty more stories about HeartMate-patients on tap amongst the Heartisans. While some, like the one Lea told, are taken from personal experience, the other, like the other two stories told here, have the character of Heartlands legends which are neither verified nor falsified but go around as urban legends.

On another occasion, Assistant Nurse Diana talked about how demanding it is to take care of mechanical help-heart patients “especially when they are not willing to cooperate”. Nurse Camilla agreed and remembered Alfred, a young man who had a mechanical help-heart implanted and who, according to Camilla’s and other stories about him that circulated the Heartlands, seems to have been a rather troublesome patient. I was amazed by the number of people who would tell stories about this particular young man¹⁵⁴. Sometimes, someone would start telling it and others would join in, creating a collective narration of a specific kind with this particular story in focus. According to this legend, Alfred refused to eat properly, he “lived dangerously during his time with the pump” and “didn’t observe the instructions that he was given”. He “rode his bike so that the drive line would get stuck in the handlebars” etc. And the worst thing of all, according to the legend, was that he failed to respond to his beeper when he was called because a heart was finally available for him, so he missed this chance for transplantation. He was, the saying goes, “having a beer at the pub with some friends”. Luckily, the next time he was beeped he responded and was successfully transplanted. A short time after receiving a new heart, however, young Alfred died. The cause of death seemed rather unclear. Some say it was cancer and

¹⁵⁴ See also pp 241-242 for yet another example of this particular story as it was told during one of the lunch breaks by Assistant Nurse Selma and Physiotherapist Lea.

others say that he suddenly refused to take his immunosuppressant medications causing his body to reject the new heart and leading to a very painful death.

Interestingly, these legends are never directly doubted or questioned but are usually told and listened to with awe. Most of the listeners seem to have found Lea's stories gripping and enjoyable. Moreover, these and other stories told in Heartlands all seem to be an enactment of collective memory (Wertsch 2008) – a reflection of the past that all Heartisans share. Many of these myths, or legends, are not documented but are passed on from mouth to mouth (Roche, et al. 2005). The purpose of these stories is to reinforce and shape those facets of Heartlands that separate Heartisans from other people in the hospital or any other place. The main properties of these stories revolve around the social, cultural, and emotional aspects of Heartisan daily work and concern path-breaking fusion of human hearts and technological breakthroughs such as HeartMate®. These stories evoke the sense of pride. Heartisan cardiologists, surgeons, anesthesiologists, nurses, and nursing assistants roam the twilight zone between human and machine, between yesterday's physiological problems and future mechanical solutions. *Fika* and lunch are ritualized breaks from the structured frame of the Heartisan workday. Through heart myths, Heartisans create a breathing space, i.e. space for revival, reflection, and sense-making.

Finally, *fika* and lunch break provide the staff with the opportunity to ventilate their opinions regarding, for instance, their disagreements with some of the doctors. Although doctors' orders are executed by the staff¹⁵⁵ without resistance, they are not always met with understanding. An individual nurse, or a physiotherapist, might occasionally make a suggestion about their part of the treatment. Still, they hardly ever engage in a direct confrontation by seriously questioning the doctor's orders. Instead, these objections are expressed among the staff themselves as a way of enacting this silent disapproval through mutual understanding. On one occasion,

¹⁵⁵ Nurses, nursing assistants, physiotherapists, dietitians etc.

Physiotherapist Clara confided to me about how she viewed Doctor Jakob's orders regarding the patient's training program as "too pushy and demanding way too much way too soon for Bengt-Erik... Doctor Jakob's all like 'Just get it on!' and it's not that simple... that's not going to help and we physiotherapists, we can see these things... we notice if the patient maybe is maybe a bit too ambitious or if he needs a push... because you must not be worn out... that's not good either!"¹⁵⁶.

Training

Training is considered the essential part of the mechanical help-heart treatment. After the operation it is particularly stressed, and regular exercise is continuously prompted by the doctors. The exercise practices are led and managed by physiotherapists. The intensity of exercise is adjusted to a patient's condition and is increased gradually as the patient gains strength. It usually starts with the patient's first breaths without the help of the respirator – for a newly-operated patient this is quite a demanding and difficult task. As the breathing gets better a patient might start with breathing gymnastics, which consists of blowing into a whistle-like plastic device in order to train the lungs. Another of the first post-operative workouts is for a patient to wiggle his or her toes and to lift up his or her hands and arms a couple of centimeters from the bed sheets. After a day or two a new exercise is initiated, in which once or twice a day the patient is assisted by a physiotherapist to sit on the edge of the bed for a minute or two. Further progress is marked by the first time a patient is able to stand up with the help of the cheering staff, usually a couple of days after the surgery. Waiting in a standing position while the staff make the bed is also one of those early exercises that are quite difficult for the patient at first, but eventually becomes easier. The next one is to stamp the feet on the floor, in combination with proper knee lifts while standing. After another couple of days, when patient is considered ready, a walk around the ward with help of a walking

¹⁵⁶ Compare with the episodes described on pp 241-242.



Figure 36: Bengt-Erik during one of his walkabouts around his room. Photograph by Haris Agic.

frame becomes a common part of daily exercise. This is also an indication that a patient now is ready to eat his or her meals in the patient canteen¹⁵⁷. Eventually, a patient is encouraged to join other thorax-operated patients in their regular gymnastics at the Department of Cardiothoracic and Vascular Surgery one floor up. Here, a mechanical help-heart patient meets lung cancer patients, bypass patients, etc. They all sit in chairs facing the physiotherapist who leads the work-out by showing how different exercises are done and by cheering on and praising the patients for their efforts. Walking up and down the stairs to other floors (*trapprövning*) is also practiced under the supervision of a physiotherapist.

There is a general sentiment among the doctors that the more intensive the training, the sooner the patient can be discharged, which generally increases the chances for the whole treatment to succeed.

¹⁵⁷ Whereas Bengt-Erik was encouraged to have his meals in the ward canteen, Maja had never had any of her meals there but was served food in her room until discharge. I never found out why this was the case.

“It’s eating, working out and going home that is on the agenda now... we can’t get soft here... this is no Sunday school!”, said Doctor Pia when Bengt-Erik arrived at the Heart Failure Ward after surgery and treatment at TICU. The professional opinion of physiotherapists regarding the patient’s general strength and the methods of exercise is expected as a natural part of the treatment and is usually also respected among the doctors and nurses. However, the general ethos among the doctors that proper, i.e. rigorous, training is the key to the success of this treatment has at times impelled them to push things beyond what physiotherapists would consider reasonable to demand from the patient in question. At times like this, a doctor would display a wish to control and direct the intensity of training while a physiotherapist might try to put up a slight resistance in the form of a polite suggestion. More often, however, physiotherapists would try to avoid direct conflict with the doctor and choose to limit their resistance to sharing their discontent about the situation with one another, with a nurse or assistant nurse (or with an anthropologist). This was quite evident in the example provided earlier (pp 241-242), when Physiotherapist Lea shared her dissatisfaction about Doctor Arvid’s pushing the patient in spite of her and her physiotherapist colleagues’ professional judgment that such intensity is unwarranted and even unrealistic. Another example, also mentioned earlier (pp 316), is when Physiotherapist Clara found Doctor Jakob’s demands on increasing the intensity of a mechanical help-heart patient’s training to be “too pushy and demanding, way too much way too soon”, risking overtiring the patient instead of serving as a means to gain strength.

SUMMARY

First, during the rites of preparation the patient is informed about the treatment. Then he or she is physiologically optimized for the treatment. And finally, the site and the people involved in the treatment are prepared. The goals of the rites of preparation are to: a) provide the patient with a sense of safety and, above all, a sense of

hope, b) transform the patient into a case mentally and physiologically suitable for this particular treatment, and c) to elude indeterminacy, which usually follows such risky treatment as implantation of a mechanical help-heart, by careful arrangement of the site and the staff so as to suit the treatment, and also command strict adherence to the established rules of conduct.

Second, during the rites of operation the surgical implantation of a mechanical help-heart is performed. In addition to being instrumental, the surgical procedure is highly communicative and normative. Through a style of performance including comedy, it systematically seeks to downplay the elements of danger and the presence of tragedy while emphasizing the image of a brave hero-surgeon who is in control. Ultimately, the performance of surgical implantation is the actualization of the Heartisan mechanistic worldview. As such it also works as the very substantiation of that worldview. All these three elements – instrumentality, communication, and formality – make the rites of operation a culturally specific ritual performance, the main property of which is its heroic drama of success – the potentiality of hope in the very moment of its actualization.

Third, during the post-operative treatment and care practices (let's call them rites of resurgence), a patient is gradually brought back from narcosis with the aim of achieving a desired grade of revitalization that will eventually lead to discharge. During the first phase of the rites of resurgence, the patient is under constant and intensive surveillance, attached to a variety of high-tech machines, and subjected to continuous tests and examinations. The daily work is performed according to the standard care routines. At the same time, the patient's situation is anything but stable, posing a number of challenges to the medical staff, who are forced to break away from the standard routines in order to meet these challenges. This is, however, not left to chance or arbitrary improvisation – the standard rites of resurgence are always backed up with an array of other rites. These are on constant stand-by, ready to be put in practice if needed.

During the second phase of the rites of resurgence the patient is subjected to strictly organized practices at the Heart Failure Ward, the main purpose of which is to get the patient 'up and moving' and ready for discharge. Ward practices consist of a complex net of daily rites, most of which are grounded in a thematic structure of information exchange – a guiding template in all rounds, logs, journals, or records. This thematic form that organizes the ward work is a safeguard against the threat implied by overlooked facts. Its form is continuously applied through the routinized repetition of daily practices as a way of ensuring a reasonable level of patient safety. Moreover, the continuous demand for facts inherent in the standardized thematic grid of these practices is an expression of a mechanistic worldview based on natural scientific paradigm. It downplays the significance of social, cultural, and emotional dimensions of illness experience while at the same time working as the substantiation of the cult of evidence. The thematic structure of information exchange and of facts selected in order to generate understanding about the misfortune and to establish a plan of action for dealing with it pervades the entire course of treatment and Heartisan practice in general. It is a way to select and assemble clinical evidence on which any further claims and decisions can be made. At the same time, the rigidly selective character of this form makes it a highly normative aspect of Heartlands practice, discriminating against all the facts that fall outside of the thematic template as irrelevant. This observation coheres strikingly well with Reynolds Whyte's explication of John Dewey's philosophy of pragmatism with regard to our ways of dealing with misfortunes: "[We] select the data from our experience that are relevant to the problem at hand. The Latin word data means 'givens' [but we should instead] think of them as 'takens', discriminated and chosen for the purpose of locating and resolving a problem" (Reynolds-Whyte 1997). In view of that, what witchcraft is for Azande (Evans-Pritchard 1976[1937]) is what blood tests, respiratory signs or patient's life-style habits of consuming tobacco, alcohol, salty, sugary, and fatty foods are for Heartisans. They are

socially relevant causes that allow intervention and provide "... the requisite ideological background to make the response logical and coherent" (1976[1937]Ibid: 25, 45).

Furthermore, behind the curtains of all ritualized activity, Heartlands folklore is kept alive through unofficial practices of storytelling, a practice which I therefore call heart myths. Myths and legends about mechanical help-heart patients from the past are evoked and told, individually and collectively. The truthfulness of these stories is never questioned. Instead, they are told and listened to with a sense of pride and admiration. They are in a way the enactment of Heartisan collective memory, and are as such not read from a documented source but are passed on from mouth to mouth with the aim of preserving the Heartisans' professional identity and making sense of their work. These stories revolve around social, cultural, and emotional aspects of daily life in Heartlands – the very same elements which are otherwise systematically downplayed by the ways in which daily routines are structured.

Central to all the rites taking place during the stage of transition is construction and maintenance of hope. The outcome of mechanical help-heart treatment is indeterminate, as it is a procedure saturated with mortal risks. Given that this indeterminacy prevents any certain knowledge about the outcome of the treatment, it needs to rely on a solid sense of hope as something to believe in. Thus, the success-stories, the rigidity of the way daily work is structured, careful classifications of reliable facts, the profusion of medical technology, heroic portrayals of skilled experts in charge of control, the cult of evidence, and heart myths are all the elements of the treatment. Their design plays an important part, directly or indirectly, in the creation and maintenance of hope.

CHAPTER SIX - REINTEGRATION

I

CONTEXTUAL ASSYMETRY

It would cost five hundred kronor for me and Cecilia to go to that party but we think it's not worth it 'coz we can't really participate fully... I get so tired as the night comes and so does Cecilia... we'll devote the time I'm home to each other instead.

BENGT-ERIK, MECHANICAL HELP-HEART PATIENT ABOUT HIS
PLANNED LEAVE OF ABSENCE

A couple of days before the weekend of Bengt-Erik's leave of absence¹⁵⁸ from the hospital he told me that the motorcycle club where he and his wife were members was throwing a forty-year jubilee party. There was excitement in his voice and an obvious glow in his eyes while he talked about this party – a contagious and moving (hence, clearly observable) kind of aspiration. He and his wife were both bikers and there was no doubt that desire to attend the party, aroused by coinciding with his leave of absence, was tugging at him. Still they chose not to go because they felt incapable of 'really participating fully'. Bengt-Erik cited his tiredness as the obstacle – a disability – preventing him from attending the party. The party was unmistakably designed for people vigorous enough to attend in an active manner, i.e. able to "participate fully". Tired newly operated mechanical help-heart patients on leave of absence just don't fit in, no matter how tempted they might be.

Upon their discharge from the hospital, mechanical help-heart patients report a strong sense of ambiguity regarding multiple aspects of their existence. From the perspective of ritual theory, while regarded as a natural part of the liminality inherent in a rite of passage, this ambiguity was expected to be eliminated through the

¹⁵⁸ Leave of absence is routinized practice that precedes final discharge (for further details, please see below).

final stage of ritual, i.e. practices of reintegration. However, the ethnographic data shows that the attempted reintegration instead repeatedly traversed into a kind of ‘social displacement’ or a ‘blind spot’ enhancing the patient’s sense of ambiguity even further. The example above illustrates one of several aspects of this existential gap. Bengt-Erik’s expressed sense of disability called for reordering of old priorities and restructuring of new daily activities – less with regard to what he would like to do and more with regard to what he was able to do. Besides disability, this gap, as examples in this chapter will show, is also characterized by patients’ ambiguity about their desired well-being, their uncertainty about risks and constant fear of deterioration, social estrangement, anxiety of being unprotected (loss of medical embrace¹⁵⁹), fear of dependency (involuntary patienthood), and also the altered sense of self. Ultimately, the examples in this chapter will be used to demonstrate how the gap itself is constructed through rigorously routinized medical practices based on medical professionals’ ever-increasing focus on specialization as a result of which most of non-physiological aspects of the illness and the treatment are systematically neglected. For the patients, with one foot in the world of the hospital and with the other stepping into the world of social ties, responsibilities, cultural norms, and values outside the clinic, these everyday-life-aspects of illness start demanding attention. Although the patients cannot escape this demand, it nevertheless remains in a blind spot for the team of medical professionals taking care of them.

BLIND SPOT

Reintegration of a person, from the liminality of hospital life back into his or her ordinary life, starts with discharge from the hospital. This means that those patients who managed to survive the treatment, be they bridge-to-transplant or destination therapy patients, are eventually, as they get better, released from the hospital

¹⁵⁹ For further details on the concept of ‘biomedical embrace’, please see below (pp 346-351).

to life at home. However, the circumstances surrounding this part of their treatment create a rather ambiguous context. First, due to regular check-up visits, follow-ups, controls, tests, additional treatments, and medicine adjustments, the patients have life long bonds to the hospital. Thus, instead of simply changing with the discharge – from hospital to home – the site for reintegration becomes dual; it is simultaneously in the hospital and at home.

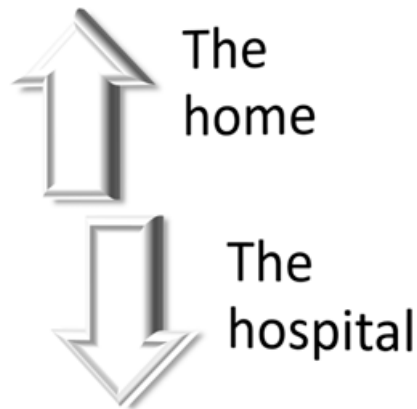


Figure 37: Contextual asymmetry

Second, the non-physiological aspects of patients' lives with mechanical help-hearts, i.e. the emotional, social, cultural, and practical, are not provided a definite space in the treatment design, mostly due to the growing focus on medical specialization. In other words, doctors and nurses lack the knowledge, the time, and the resources for dealing with these aspects. Third, the demands of social life at home and within the community that surface with reintegration turn out for many patients to be rather hard to manage. This contextual asymmetry (hospital/home) induces a particular kind of existential asymmetry (patient/non-patient; healthy/sick; dependent/independent; safe/at risk) which instead of freeing the patient from liminal ambiguity, further prolongs and amplifies his or her betwixt-and-between sociocultural status. The tensions created

between these two disparate sociocultural structures are usually experienced as quite a heavy load – a pitfall of the gaps left unminded.

Let's, for the sake of clarity, take a brief look in the rearview mirror and look at the outline of the entire rite of passage. During the first stage of treatment (separation), the patient was initiated into a Heartisan culture. In order to truly understand and submit to Heartisan rules, norms and values – a prerequisite for the success of a treatment – the sick person had to become one. By receiving the status of a Heartisan, the patient was provided a particular place and a role among the Heartisans – status position as a patient in a Heartisan culture. During the second stage (transition), the patient was subjected to strict procedures of a Heartisan treatment based on a mechanistic paradigm of illness. There it is defined solely in terms of the objective, measurable data of the natural sciences while the subjective experience of illness and its sociocultural significance was systematically downplayed. Thus, by being made socially invisible and ambiguous, the patient was “ground down” into a crude matter to be formed – suitable for transition from dying into living (Turner 1997[1969]: 37). By opening the window of opportunity in a hopeless situation the ritual gives hope to the hopeless.

During the third and final stage (reintegration), which is the focus of this chapter, a patient returns to his or her ordinary life. Here, various unanticipated challenges emerge as all the aspects of illness and treatment that were downplayed during the transitory course of the treatment make themselves known again. What happens upon return is that the temporarily ascribed status of a Heartisan patient splits in two, into Heartisanship and patienthood. Dehospitalized, the patient loses his or her Heartisanship, the temporary status position of a Heartisan. At the same time the patienthood still sticks like glue. Hence, instead of a smooth return to ordinary life with new social status, a person finds him- or herself partly dislocated in a social blind spot in between two worlds.

A number of implications follow. First, with release, a patient-hospital relationship is deeply altered. No longer a Heartisan-patient,

i.e. hospitalized patient, a person loses a great deal of the advantages of round-the-clock attention, surveillance, and care. Second, with loss of Heartisan-patient status position, a person also loses the privilege of special treatment, sympathy, and relief from responsibilities among friends and family. Third, as the treatment is not yet completed, a person remains closely tied to the hospital. This means that the person's status position as a patient is not lost with release from the hospital. For instance, a person visiting the hospital for a check-up visit is formally referred to as a HeartMate-patient (See Figures 18 and 21). For many patients this provides, at first, the comfort of being watched over regularly by medical experts. With time, however, this gaze of comfort turns into a burden of involuntary patienthood. The better a person gets, the more apparent and repressive their unending patienthood and regular encounters with the health care system become. Altogether, this dehospitalized patienthood is a condition that turns out to be quite complex and hard to handle for many patients.

Reintegration is a third and final group of practices that complete the tripartite healing ritual of mechanical help-heart treatment. Its purpose is to help reunite the person with his or her ordinary life. As a group of practices, reintegration can be presented like this:

1. **Discharge:**
 - a. Leave of absence
 - b. Going home
2. **Between two worlds:**
 - a. Life at home
 - b. Check-up visits

Nevertheless, more than being merely a practice (studied through participant observation), reintegration is also a phenomenon that a person undergoing the process of reintegration is experiencing (studied through informal interviews). If successful, it is supposed to bring the patients back to their lives – to lead them back on track. In the case of mechanical help-heart patients, however, this sense is

V10

ÅRSKONTROLL Hjärtrplanterad patient

Namn [REDACTED] Födelsedata [REDACTED]

HTX-datum	Inl datum	Temp	Vikt	kg
Undersökning	Gör	Remiss lämnad	Tid för undersökning	
Hb, LPK, TPK, B-celler				
Na, K, Krea, Urea, Albumin, CRP, LD, Bilirubin, ALP, ASAT, ALAT, Ca				
Lipidstatus (kolesterol, triglycerider, HDL)				
Cyklosporinkoncentration			4/3	08:30 +
IOHEXOL-clearance	4h	X	3/3	11:45 12:30
Urinstatus (urinsticka)				
Övriga prover, fb-glukos				
Hudkonsult	X		4/3	13 ⁰⁰
Odontologisk konsult sjukhustandvården, dr L Andersson	X		4/3	08:30
EKG				
EKO	X		4/3	11:00
Arbetsprov			4/3	9:30
Hjärtkat				
Coronarangiografi				
Hjärtmuskelbiopsi				
Cor/Pulm röntgen	X		3/3	1040
Gynekologisk konsultation (kvinnor)				
PR (män)				
Dietist	X		3/3	
Sjukgymnast	X		3/3	

Läkare: _____

Figure 38: 'Annual control' check-list for the tests and examinations to be performed on a heart transplanted person. Note how the designation of 'patient' is still being assigned to the person (upper right corner). This is a standard form and this detail shows how a person after completed mechanical help-heart treatment and the subsequent heart transplantation is assigned life-long patienthood irrespective of the amount of time that has passed since the transplantation.

by the force of the dual context (hospital/home) split into two rather conflicting senses – simultaneous feelings of hope and despair.

The dualism of this new mode of existence is spatiotemporal. Its spatial dualism is reflected in the patient's existence in between two settings – the home and the clinic. Its temporal dualism, on the other hand, is reflected in the patient's uncompleted transition from the past (death, illness, despair) to the future (life, health, hope). The two different sociocultural contexts in which the process of reintegration takes place are, instead of being chronologically ordered in time¹⁶⁰, taking place synchronously as they are intimately entangled in a paradoxical relation of mutual dependence and negation. Thus the second point listed above – “Between the worlds” – is more than merely a final set of practices of the mechanical help-heart treatment – it stands for the new mode of existence.

The meaning inherent in a mechanical help-heart (device and a treatment) is contested in this tension between two worlds where negotiation between hope and despair is constant. Most importantly, although this tension does exist in discourses among clinical and experimental medicine, the medical industrial complex, mass media, popular culture and general public, for each and every one of the mechanical help-heart patients it is a tension that they embody and live with.

Methodological adjustment

Due to this contextual asymmetry I needed to make some adjustments in my methodological approach. So I provided more space for informal interviews alongside the (thus far dominant) focus on practice. Conducting participant observation of patients' everyday lives at home with their mechanical help-hearts turned out to be rather difficult as I felt obliged to make the most out of my limited time in Heartlands. Still, this didn't leave me short of practices to observe – I was able to follow closely and take notes of the practices

¹⁶⁰ A chronological succession of events – after life in the hospital comes life at home, followed by check-up visits, etc.

surrounding leave of absence and discharge. I also observed the clinical check-ups of a significant number of already discharged mechanical help-heart/heart transplant¹⁶¹ patients. During the observations I would take the opportunity to invite the patients to an informal interview so that they could let me come a bit closer to their lives with mechanical help-hearts outside the hospital. These talks were then conducted in a rather casual manner in fairly isolated parts of the ward or during a lunch in a Heartlands canteen. I also obtained two short autobiographically written accounts of two patients' mechanical help-heart treatment processes. Both were sent to me by email. Finally, one of the patients preferred to be interviewed at his home where we met couple of weeks after his check-up visit and had a talk that was nearly four hours long. This slight methodological slide resembles the fuzziness surrounding the in between situation of the patients. As their practical lives outside the hospital were out of reach for my first-hand participation and observation, the closest way to understand it was to make use of their ties to the hospital. Through that, I could pay attention to their own accounts about their practical lives with mechanical help-hearts, about the daily practices they deemed relevant to their mechanical help-hearts and also to their well-being more generally. Thus, I could learn about the ways in which they experienced their lives with (and after) a mechanical help-heart, as well as about their attitudes towards it and their ways of reasoning about it.

All this considered, this chapter combines, to a greater degree than the previous ones, two distinct yet interrelated focal units of analysis: a) patients' own accounts of their experience of mechanical help-heart treatment and of their lives after the treatment; with b) clinical practices surrounding these last stages of the treatment. This methodological shift adds slightly modified tone and color to the whole study. Above all, patients' experiences vary, providing an

¹⁶¹ This includes both the patients who are still living with their mechanical help-hearts and those who have explanted their mechanical help-hearts and instead received a heart transplant.

interesting array of perspectives and themes. For instance, after his two-day leave of absence Bengt-Erik returned to the hospital. This was my opportunity to talk to him about how he experienced being home for the first time after the surgery. He told me about uncertainty inherent in life at home with a mechanical help-heart and also about how it was not quite what he was hoping for. Maja, on the other hand, never took a leave of absence prior to discharge. I met Lennart during one of his regular check-ups and he told me about how the treatment had changed him as a person. I also met Emelie – the only destination therapy patient among all my informants – during one of her check-ups, and she spoke about the burdens of everyday life at home with a mechanical help-heart and the general unawareness about these things. I met Moa during her check-up (where she also was hospitalized for a couple of days due to an infection); she complained quite a lot about anxiety and fear of dying, but also talked about the doctors and nurses in tones of appreciation. Niklas is yet another mechanical help-heart/heart transplant patient whom I have met during his check-up and whom I interviewed in his home a couple of weeks later. His story is one of the successful mechanical help-heart treatments – but it is also a story about involuntary patienthood and fear of dependency. In general, this chapter is based on an ethnographic account of practices surrounding the discharge of two mechanical help-heart patients and check-ups of four already discharged mechanical help-heart/heart transplant patients, as well as on the conversations that I have had with all of them. Although the experiences differ from account to account, some features of life with mechanical help-heart seem more common than others.

II DISCHARGE

Leaving the hospital requires, and therefore also signals, a certain degree of recovery. Thus, discharge is primarily regarded as something unquestionably good. Then again, to a patient it also means that the continuous access to medical expertise and high-tech equipment ensuring that nothing goes wrong, and/or taking care of



Figure 39: Twice-a-day clinical ritual of wound sanitizing and dressing, here performed on a Bengt-Erik by a nurse at the Heart Failure Ward. This clinical ritual is expected to be learned and performed by the patient him or herself after discharge. Also during the regular check-up visits, a transplantation nurse would perform this ritual as a way of monitoring the state of the ever so critical wound. Photographs by Haris Agic.

anything that might, is no longer there for them. Patients find this rather unsettling. What's more, leaving the hospital also means that patients are increasingly expected to take more responsibility for taking care of themselves. Besides learning and complying with new daily routines such as pump maintenance, wound cleaning and dressing, and observance of a new drug regimen, the old daily tasks such as personal hygiene, household work, and observing the regained relational obligations and social commitment towards friends and family need to be dealt with. Thus, before they are finally discharged from the hospital, patients are usually granted a leave of absence as a test of the life to come.

LEAVE OF ABSENCE

When a patient has gained enough physical strength to manage looking after his or her pump, the PBU, battery changing, daily driveline wound cleaning and dressing, combined with the basic daily tasks required for life at home – it is time for standardized leave of absence. As Doctor Jakob explained to Bengt-Erik just before his leave of absence for a weekend, “The idea is to spend a day or two at home to try and see how things work out and what doesn't work, so that these things can be fixed the following week on your return to the hospital... the idea is to get you home permanently”.

In the quote presented at the beginning of this chapter, where Bengt-Erik shared his concern about not attending a motorcycle jubilee party, he also says another interesting thing, namely, “[Cecilia and I will] devote the time I'm home to each other instead [of attending the party]”. This is yet another element in Bengt-Erik's story that nuances the situation even more. The power of longing accompanied with relational obligations between him and his wife needed to be honored. Tired as they both were due to everything that Bengt-Erik has been through recently, they have also been apart from each other for quite some time now. Taking on the challenge of attending the party, the expectations of which they just could not meet, would besides wearing them out probably stand in the way of

their own closeness. Thus, the choice was jointly made to devote the short time they had at their disposal to each other instead. Still, this turned out to be a bit more complicated than Bengt-Erik first anticipated.

After spending a weekend at home, Bengt-Erik was back in his hospital room. He complained that his leave of absence wasn't quite what he was hoping for, "The weekend was nice... we were at the home of one of Cecilia's daughters and we ate cake... it was nice... still... it wasn't what I thought it'd be... I wanted us to have some time on our own... but there went that weekend... at least we had yesterday". Besides facing a whole new set of practical challenges regarding his new kind of life with a mechanical help-heart, Bengt-Erik realized that a return home also meant going back to his former social roles and status positions – in this case that of a husband and a stepfather. He was expected to resuming his old social commitments and kinship obligations in spite of his new status as a mechanical help-heart patient, his turbulent and fragile mode of existence that above all seems quite different from those of the people around him. Besides the challenge of negotiating his place in the web of his social relations outside the hospital, life at home had a number of unanticipated practical challenges as well.

During the first ward round after his return, Bengt-Erik complained about the thunderstorm that took place during his leave of absence. He was worried because he literally had to be plugged via the PBU straight into the electrical power socket during the night in order to keep his mechanical help-heart spinning. His batteries could not last through the night¹⁶². He said that he got scared during the

¹⁶² An explanation of this was given during the 2011 Ventricular Assist Device meeting held annually by one of the manufacturers of mechanical help-hearts in Sweden for doctors and nurses working with these devices. It was said that the reason why batteries with such power and durability were still not available was because they would last too long to be profitable for the battery manufacturing companies. Batteries need to be replaced frequently in order for their manufacturers to earn money. The more frequently they are replaced, the more money they earn. Thus, the kind of research that is required to realize the

thunderstorm because the lightning could have hit the electric circuit of his house – the circuit onto which he is connected: “I need a plan of action so that I know what to do in a situation like that”, he said. Doctor Therese promised to ask the perfusionists to take care of this: “When it comes to all this technical stuff, we usually ask perfusionists to handle that”. After the rounds, I stayed to talk to Bengt-Erik for a while. He continued expressing his worries: “I’m worried about this thunderstorm thing and I have a whole lot of questions about that... what should I do... ‘coz I’m connected directly to the socket... it’s almost like I’d need some special type of lightning conductor or some protection... sure, I could switch to batteries but what if the storm lasts a long time”.

It was upon his first return home that Bengt-Erik was confronted with the reality of social life and the culture of the healthy. Relational duties and responsibilities inherent to this life suddenly commanded attention and obedience. However, he didn’t seem ready to plunge into the white waters of this world; the flow was a bit too rapid and turbulent for Bengt-Erik to handle. While in the hospital it was perhaps much easier to be exempt from the norms and rules that people adhere to outside. The hospitals are generally less demanding as they are a “simplified setting” with “few tasks” for a patient to accomplish (Murphy 1987: 58). On the outside, however, things are different. The sheer act of taking a leave of absence signals that the process of recovery is progressing, announcing the coming of full reintegration just around the bend. But Bengt-Erik just wasn’t ready. In spite of his physiological progress, he was not yet healthy. And in spite of his yearning to come home, the home was not quite what he hoped it would be. He was still fragile, dependent on technology and medical attention, vulnerable to infections, sudden physiological changes, at risk from inhospitable yet omnipresent everyday life circumstances such as storms, uncharged batteries, late trains, an empty gas tank, or an unexplainable pump failure. The structures of

dream of batteries with such power and durability is neither prompted nor funded by battery manufacturing companies.

the world outside the hospital – be it the structure of transport and communications, the structure of environmental planning, design and construction, or the structure of politics, the economy and variety of institutions, social formations and status positions – is just not designed for Bengt-Erik. This insight shook me quite hard because the more I took some of the most basic things for granted – such as taking a train to a nearby city or sleeping through a stormy night – the more bizarre and uncanny Bengt-Erik's limitations looked. I felt the absurdity of such living conditions while listening to Bengt-Erik's worried voice talking about the importance of extra batteries or the fear of an empty gas tank somewhere along a deserted road. The whole concept of dependency on a mobile kind of power supply such as batteries that was thus far known to me felt ridiculous in face of the kind of power dependency Bengt-Erik was living with. This was more than just a difference in perspectives, more than a perceptual parallax shift – the implication of this disparity was deeply existential. While my understanding of the concept of discharged batteries brings forth images of temporary disconnectedness from the world of social media (such as the mobile phone and email), to Bengt-Erik it is a matter of life and death. It was clear to me that he was still not quite like the others whose world he now had entered. His account portrays a struggle between his physiological self (a body with a sick heart relying on the uncertain workings of a mechanical help-heart just to stay alive) and his complex relational, and hence multiple, self (a partner in love, a stepfather, a biker). This was a forewarning of what a life at home with a mechanical help-heart might be like.

Although a leave of absence provides short glimpses of everyday life at home with family, it doesn't quite yet mean a return to the ordinary course of things – to life as it once was. Its practical purpose is to function as a test period so that the patient and his or her family can sense what it is going to be like living at home. Socially and emotionally it seems rather to revolve around learning how to cope with daily life without the constant monitoring and assistance of medical doctors and nurses. It is about enduring the hardships of the

ongoing treatment with the help of the family and also about developing individual and collective strategies that can help one make it through the day. It is about maintaining strength and hope in the face of adversity and uncertainty.

Mechanical help-heart patients usually welcome their first leave of absence for two main reasons. First it is a ritual mark of the fact that they are getting better – a tiny step in the right direction. It is a comforting voice saying: “It’s working! You’re going to be alright!”. Second, it is an opportunity for them to spend time at home with their families. However, leave of absence is also met with a sense of unease which, besides being explicitly expressed, is most noticeable in patients’ efforts to ask various questions, sometimes repeating the same ones over and over again to make sure they didn’t forget anything important. The stakes are too high for the patients to allow an accident of leaving out something important. It seems to be that their sense of unease stems from here. The hope that was enclosed in this particular high-tech life-saving device and realized in practice through implantation was thus far embedded in constant and total medical surveillance and control. Being surrounded by medical experts in a modern clinical environment provided a sense of safety that is crucial to their sense of hope. The leave of absence, a practice that temporarily removes the patient from this safety, apparently also blows holes in this freshly instilled sense of hope.

GOING HOME

I am a little worried about moving home, but it’s probably gonna be alright... there’s so much with everything... but Thor [Maja’s husband]... he’s so good with all these machines!

MAJA, MECHANICAL HELP-HEART PATIENT ABOUT HER PLANNED
DISCHARGE

Maja, another mechanical help-heart patient, was also encouraged to take a leave of absence. She worried, even more noticeably than Bengt-Erik, about leaving the hospital. Seeing this, Doctor Arvid explained to her that it was not compulsory and that it was completely

up to her whether she agreed to take a leave of absence or not. In case she did, she could also come back to the hospital earlier than agreed if she felt more at ease that way. She never went. Instead, Maja chose to stay in the hospital until the time came for her final discharge. She was obviously frightened by losing the protection that the medical experts and high-tech clinical environment provided. Just before her discharge, like Bengt-Erik, she tried to manage her worries by asking a great deal of practical questions. She was covering herself against a risk of missing information on all the details she was now responsible for keeping a check on, with no one else to rely on but herself and perhaps some of her closest kin.

Maja was clearly clinging to the safety of medical expertise and technology in the hospital for as long as she could. Upon final discharge, she comforted herself with the fact that her husband, who also is a medical doctor and “good with all these machines”, is going to be there for her, adding a new dimension to their marital relationship – the need for technology managing. What becomes apparent in both Maja’s and Bengt-Erik’s cases is the ultimate dependence on technology and also additional dependence created by this technology. The need for technological maintenance and clinical surveillance at home worried them both. New fields of challenges opened as the relations at home had to be renegotiated and machines had to be figured out and managed. Things like a local bikers club party, a romantic evening at home, a thunderstorm, electric circuits, a stepdaughter, and a spouse have suddenly acquired a whole new set of labels. The return home and reencounter with the familiar settings, objects, and people had made them aware of the real scope of their situation. Although the leave of absence was designed to work as a trial before the discharge, it seems as if the real trial was yet to come with life after the discharge – their lives at home.

III BETWEEN TWO WORLDS

She is doing fine and during all this time has not used any antibiotics... but still, it's not like she is living a fully ordinary life.
CHIEF CARDIOLOGIST ABOUT EMELIE, A 'DESTINATION THERAPY'
MECHANICAL HELP-HEART PATIENT

LIFE AT HOME

As the examples of Bengt-Erik and Maja already showed, reintegration might be perceived as rather burdensome, posing a whole new set of challenges for the patient. Symptoms and signs of improvement, such as increasing strength and mobility, stabilized physiological condition, and lust for life are regarded as markers suggesting that the patient's further progress is not as much the responsibility of Heartisans alone. Instead, concurrently with this progress, the patient is increasingly expected and persuaded to take over the responsibility for his or her condition. Hence, getting better means losing the unlimited round-the-clock medical attention and protection. Heartisans view the patient as no longer suitable for the world of the hospital. In fact, a prolonged stay in the hospital is even considered hazardous to treatment as a whole. Therefore, Heartisans share the idea that the sooner the patient gets home the better. As the patient is increasingly expected to pull some weight and rely less on the immediate assistance of Heartisans, the sense of safety and hope brought by total medical care is challenged by the sense of ever growing omnipresence of danger and unease.

Emelie, a young woman in her early thirties, was the only person in the county at the time of my fieldwork who was living with a mechanical help-heart. Emelie didn't qualify for a heart transplant because she was a breast cancer survivor – the treatment of which had, ironically, caused her acute heart failure. Because the planned post-LVAD heart transplant treatment would necessitate taking immunosuppressants permanently, Emelie was found ineligible for transplant – a suppression of her immune system would most

probably bring her cancer back and kill her. She was one of the so called *destination therapy* patients, bound to live with her mechanical help-heart indefinitely. Informally it was said that after five years of being cancer-free, a possible heart transplantation might be discussed again. Emelie had just completed her second year with a mechanical help-heart and had about three years to go. Given the poor survival rates of long-term treatment with mechanical help-hearts (pp 17), the odds for Emelie making it were not so good. Still, the vision of an eventual transplant was what she now hoped for.

I have seen Emelie in news broadcasts, in the newspaper, in Heartland's information movie about mechanical help-heart treatment, and also in person in Heartlands during her regular check-up visits. This young woman is probably one of the most successful cases of this kind of treatment in the world. She managed to make it through more than two years with her mechanical help-heart without any really dangerous complications; she had only some occasional minor skin irritation at the driveline exit and a tiny crack in the outer coating of the driveline. What's more, she has managed to lead a life at home, in a nice house at the countryside with her husband and two dogs, an award-winning German shepherd and a little shepherd puppy. Besides training and competing with her German shepherd, Emelie is also a member of a folk dance troupe, practicing and giving live performances regularly. Still, in spite of all the activity, her life at home poses a number of challenges that she needs to meet. For instance, as her case was discussed during one of the weekly HeartMate-meetings, Doctor Jakob reported that Emelie was concerned about her disability pension, as she was having difficulties in negotiating it with the Swedish Social Insurance Agency. Furthermore, Doctor Jakob added, "She is doing fine and during all this time has not used any antibiotics... but still, it's not like she is living a completely ordinary life... perhaps she should get out more... maybe work a couple of hours a day or something". Here, it is evident that Emelie was not granted any exemption from the public authorities just because of her mechanical help-heart. On the

contrary, the welfare system – the same system that had made her treatment possible – is continuously contesting her disability, forcing her to give good reasons for receiving her disability pension. The better she gets and the more she can devote herself to her hobbies, the more she has to defend and legitimize her rights for receiving economic support from the state. Moreover, Doctor Jakob's remark reveals the underlying cultural ethos so characteristic of Sweden, where work plays a great role in the shaping of a welfare society. A working person is not living off government economic help but is contributing to its growth. Thus, work is valued as a moral virtue.

During another HeartMate-meeting, Doctor Jakob informed the staff about Emelie's application for an allowance to purchase a lightning conductor in order to protect her ground fault circuit-interrupter. A lightning bolt striking the home power circuit could otherwise cause serious damage to this device, the only thing protecting Emelie from a severe electric shock while plugged into the power system at night. Unfortunately, Emelie's application was turned down by the Swedish Social Insurance Agency.

The thunderstorm problems that Emelie was having were identical to Bengt-Erik's. As mechanical help-hearts need a power supply to run, mechanical help-heart patients are dependent on securing constant access to electrical power. At the same time, in order for this access to be secure and safe they need to take precautionary measures which they cannot afford on their own. So their dependence has now reached yet another level – financial one. Both patients were, in this case, economically dependent on an allowance for purchase of a lightning conductor. This, however, was not acknowledged by Swedish Social Insurance Agency as something that the state should pay for. The first time I met Emelie, she complained about how most people are unaware of all the things that she needs to struggle with every day, "... for example, how it is to have to negotiate with the Swedish Social Insurance Agency about the disability pension and this thing with the lightning conductor and all". These things are clearly very important for Emelie and yet, somehow, they escape the

Heartisan jurisdiction – after all, what they do is mend sick hearts, not change laws. This is one of the examples of how a reintegrating patient can get stuck between two worlds, belonging to a certain extent to both of them, yet not quite fully to either.

Upon reencountering the world of the healthy, with its relational environment that is differently socially structured from that of the hospital, the patient encounters the world, which requires his or her adherence to its rules and norms. To truly belong, the patient needs to please his or her new social milieu by following the same cultural conventions and rules as other members of society. Not contributing to the group risks weakening the patient's sense of belonging to a community and, thus, rendering them less important – this is where negotiation for consideration and understanding begins.

Ironically, rather than being terminated upon the reintegration into the regular life at home, the liminality becomes even more tangible. Instead of providing a final escape from the ambiguity of liminality, regular life at home becomes a heavy burden. This sense of finding the regular life at home after the operation to be quite hard to cope with was expressed explicitly by Lennart, former mechanical help-heart patient. He had, besides mechanical help-heart treatment, also survived the subsequent heart transplantation. Lennart, whom I met during one of his check-up visits, told me about how everything he had been through had changed him radically as a person – to the extent that no one could stand him anymore. Ultimately, this had turned him into a case of paranoia, he said. He also said that the long-awaited relief that was expected to come at the end of the treatment never came. His marriage had suffered so much from his condition that he and his wife had entered marriage counseling. These sessions had helped him realize, he added, that his new behavior is unreasonable. It all ended up with him feeling relentlessly slighted and completely misunderstood, and blaming everybody for his situation.

Lennart: I have mental issues ‘coz I feel... they call me overly sensitive [*blödigt*] if I ask for a favor... above all I felt

that I was being accused... and you just take all the shit you can think of to your heart... that's my biggest problem... there's no one who could've helped me with that... and eventually I get everybody against me so I had to do something about it... somehow... They are demanding that I do something with my life and not let everything depend on the health care system... I'm bothered by unfairness... I felt very unfairly treated and it was partly my own fault because I went out very strong with "I'm healthy" and I'm this and that, although I really am not. Mentally, I'm really weak! And I get to take loads of punches... and I can't take them... but I keep my mask on and in the end I break down instead... I had talked to a counselor or two at my hometown hospital and then also a psychologist... a therapist... and those are also people with different views on things... in the beginning it was quite helpful but... his ultimate conclusion was like "You must suffer with this! You just take it!"... I don't know... up until one year ago I was doing some work on the house and the garden... really beautiful... but since then I haven't done a thing... I've just been spinning around and pondering about this shit... for the last couple of months it's gotten worse and I've also had this little operation... in my stomach... there was this stomach polyp and... and I was very worried about it 'coz all this kind of stuff can turn into a cancer, you know... so that's my problem... it was the first pump [mechanical help-heart]... you see I nearly died... I was gone... that was when... my life... I was completely... more or less dead, you see... and that had caused the air bubbles... I couldn't see it myself at first but my wife said "Your personality has changed!", and that was true

but these things are nothing you just easily accept... but I am changed... and it is most definitely from this whole circus that I've been through... that's what it was, can't be anything else... everything comes with a price.

(Excerpted and transcribed from audio recording)

“Everything comes with a price”, Lennart said. The price that he felt he had to pay was a personality and, as an effect of it, a damaged position in the social structure at home. He also described how he confused getting better and going home with being healthy – a mirage which got him into trouble with the increasing expectations from everybody that he should do something with his life, take charge, and take responsibility. What everybody didn't know was that Lennart was not quite ready for that. He was still feeling alone, vulnerable, and dependent on the health care system. That appears to be why Lennart felt like a victim of unfairness, wrongly accused of being passive and too demanding. Lennart kept turning to the hospital doctors and nurses as the only sources of safety and hope as the demands from everybody on his own individual independence and responsibility kept increasing. At first, these expectations were neither just nor reasonable to him. Eventually, he learned to blame himself for falling short of understanding and being way too sensitive due to his personality change, which he believed was caused by air bubbles generated from the mechanical help-heart that somehow damaged his brain. Thus, his personality change is the physiologically explainable problem that he now had accepted as a way of making sense of his situation.

This strategy appears to be quite common amongst the Heartlands patients in general, especially amongst the end-stage heart failure patients. Threatened by death, they tend to display a general affective response to using new biotechnologies that are offered to them by biomedical experts as a way of managing their problems – in

this case a salvage therapy of mechanical help-heart implantation. Consequently, same response is directed to professionals themselves. Anthropologist Mary-Jo DelVecchio Good describes this phenomenon as simultaneous ‘embracing’ and ‘being embraced by’ biotechnology – a result of the deeply-rooted American cultural fondness of cutting-edge medicine and experimental clinical science (DelVecchio Good 2001). Not only are the patients systematically being guided into this biotechnical embrace; they are also readily embracing the biotechnology as their very last resort. This brings back to mind Peter’s expression of trust in doctors in an episode illustrated earlier (see p 196) when he said to his cardiologist, regarding the risks inherent in life with implanted defibrillator, “You [the doctors] are the ones who decide what’s the best thing for me”. Bengt-Erik didn’t leave just the practical decisions to doctors but also the thinking about the future: “... how long I’ll live, I’m not going to ponder on that... I’ve left that to those who know a little bit more about these things”. Everything takes place as if this strategy stems from patients’ sense of being overpowered by fear and uncertainty in the face of life-threatening illness – a situation where experienced lack of knowledge, characteristic of lay people in biomedically dominated societies, narrows down their action space to the point of total dependence. The power of knowledge that medical professionals have is obviously regarded as something – perhaps the only thing – to rely on. This is reflected in Peter’s own words during the ultra-sound examination mentioned earlier (see p 191): “Those numbers [on the ultra-sound screen] don’t mean a thing to me. I guess I’ll just have to wait and see what they [the doctors] say later on”.

Not only do these patients seek refuge in the potency of biomedicine to provide practical solutions to their problems – they grip the biomedical explanations as the last sensible lifelines to be had. Or in a word, they entrust the doctors with their lives as they rely on: 1) their concrete practical guidelines for a plainly corporal ‘what to do’, as well as on 2) their metaphysical explanatory models for ‘what to think/feel’. Timid from uncertainty brought by the threat of death,

most of the Heartlands patients clearly prefer receding from the responsibility of commanding the helms of their boats. Instead, they invest all their hope and trust in doctors and in the power of their sophisticated tools – high-tech devices and high-tech treatments. The captains become but passengers¹⁶³.

Clinging to hope

“I got better after the operation but I’m ill most of the time”

MOA, FORMER MECHANICAL HELP-HEART PATIENT

While patients are embracing and are being embraced by the biotechnology, the following examples will serve to demonstrate how their relation to biotechnology and doctors is a matter of interpretation and is increasingly negotiated after their discharge from the hospital. Another example of a patient’s clinging to this biotechnical embrace while demands for taking action and responsibility after discharge kept increasing is presented in the case of Moa. Moa is a young woman in her early thirties, a former mechanical help-heart and subsequent heart transplantation patient. At the time I met her at the Heart Failure Ward, where she was hospitalized for examination and surveillance due to an infection, she kept complaining about being burdened by anxiety [*ångest*] stressing about not being able to cope with it on her own, and said that she needed help to get rid of it. It was quite clear that she felt powerless and incapable of taking responsibility for coming to terms with her anxiety. For this reason she kept turning to the medical team of professionals who were involved in her mechanical help-heart treatment. These were the people who once saved her life, the people she trusted. When I asked Moa why she was feeling anxious she answered without hesitation that she was afraid that she might die, “The first thing I think of is: ‘Is it rejection!’... I got better after the operation but I’m ill most of the time... I’ve been sick all fall and

¹⁶³ See also the discussion of the idiomatic Swedish expression “att vara med på tåget” in which patients, indeed, are rendered passengers (pp 195-196).

winter”. She always felt tense, she said, and didn’t know how to relax: “Will you please ask Lea [the physiotherapist] to help me? She must teach me how to relax... I just can’t relax!”.

Moa complained continuously about anxiety and fear of dying. She often described life as unbearable and her condition as agonizing. Compelled by despair caused by the sense of always-present threat of death, she kept returning to Heartisans, clinging for her life to the only source of hope she knew. Throughout her entire mechanical help-heart treatment Moa suffered a great deal of pain and her situation was always critical. Hence, it wasn’t until her heart transplant that she got to leave the hospital for life at home. However, Moa’s condition never stabilized fully and she was constantly being tormented by her poor health. She felt physically weak and suffered continuously from colds and fevers. She looked for refuge from the anxiety and despair that this had caused her in the embrace of the medical team, whom she often talked about in adoring terms, describing them as “wonderful” and “fantastic”. These were the people who had saved her life and it was quite obvious that she sought comfort in their attention.

In the meantime, the observations made by the team revolved around mechanistic physiological facts such as that it was probably Moa’s reduced bodily resistance, due to her intake of immunosuppressants, that was causing her recurrent fevers. Thus, Moa’s condition was explained in medical terms. Furthermore, she was quite often described as “depressive” or suffering from “depression” by her cardiologist doctors and sometimes also by the nurses. Besides being generally regarded as low-spirited Moa was described as having malfunctioning perception and, ultimately, as being mentally challenged: “... Something’s wrong with her, mentally... she’s been phoning the reception for every little thing!” said one of the cardiologists. The same perspective was also used to question her subjective experience of her condition: “... yes, she’s having a tough time, but is she showing any symptoms?!” said one of the doctors with a raised voice, demonstrating annoyance regarding Moa’s cries

for help, implying that her having a tough time is not a medical concern as there are no clear clinically observable symptoms. Final orders given to the staff by one of the chief cardiologists were clear: “This [the case of Moa] is completely new to us. It is of great importance that we are very clear in our communication with her. No abstract discussions! Short sentences! It is important to declare who calls the shots and to demonstrate clearly that things are not negotiable. So what I want you to do while she’s here is to prepare for discharge and mobilize!”.

This posture reflects, on the one hand, a long-standing biomedical paradigm which, as described by Foucault, has dominated clinical practice ever since the dawn of anatomico-clinical perception brought by the introduction of autopsy as the warrant of diagnosis in the eighteenth century (2006[1963]: 152-182). Examination methods used by doctors in clinics sought to locate and observe signs in order to draw near to the disease itself. Clinically, symptoms were observed showing the “living body of the disease” while anatomical practice could only reveal the disease through dissection of the corpse (Ibid: 164). The development of modern diagnostic technology enabled clinicians to “see” the disease – the lesion – without opening up a corpse, thus enhancing their power and attesting to the potency of biomedicine. At the same time, this development eclipsed the subjective experience of a person as a social subject “... in the existential context of their life and suffering” (Honkasalo 2001: 324) while amplifying the visibility of the lesion as the primary, if not the only, warrant of diagnosis. A living person, a human being experiencing the pain, remains invisible. To earn biomedical recognition, Moa’s subjective experience must be “‘seen’ in the body” (Honkasalo 2001). While Moa felt dependent on medical attention due to her being constantly ill and suffering from fear of dying and anxiety, this dependence was, due to the clinical invisibility of her suffering – or, more precisely, due to the biomedical blindness to her suffering – regarded as exaggerated and even as a property of a mental disorder. On the other hand, the invisibility was not only

caused by the technicalities of diagnostic procedure but also by the very structure of medical knowledge with its ever-increasing focus on medical specialization. Heartlands cardiologists deal with human hearts. Their focus here is determined by two fundamental understandings:

- 1) Qualitative: the range of their perception of a patient's condition is by and large limited to their strictly physiological view of human body.
- 2) Quantitative: their primary concern lies not with the entire human body but with an anatomically well-defined portion, namely the heart.

The benefits of increasing medical specialization are in the main widely accepted. However, Moa's case reveals one potentially very dangerous downside of such expert knowledge, namely a risk that those aspects of a person's sense of body-self and illness experience which are not already part of such a constricted focal range of certain medical specialization might simply disappear from sight. Moreover, this was not the first time this sentiment was expressed by the doctors. On several occasions, both prior to and after Moa's case, I have heard cardiologists say things like, "I don't think we as cardiologists should deal with something that we don't have the competence for. Instead, we should be focusing on the heart-related matters", or in an observably upset manner. "He [the patient] is more interested in his diarrhea than in his heart failure", or "We can't help you with your stomach problems here because we only know how to deal with hearts". In the meantime, much of the patient's own experience of his/her condition remains in the medical blind spot, at the outskirts of significance. This analysis echoes the findings of Masana (2010) about how illness invisibility (social and/or clinical) delegitimizes the body-self and illness experience. Masana is particularly critical of the kind of attitude that people suffering from invisible chronic illnesses are usually confronted with: "It's all in your head./ This, you are provoking to yourself. / You just need a more

positive attitude””, since these expressions “[...] put the blame on sick persons as responsible of their suffering and illness situation” (Ibid: 138).

Almost the entire time she was hospitalized Moa complained to everybody about her unbearable situation. In between her regular stays in Heartlands, while living at home, Moa was very persistent in her attempts to seek help from the Heartisans by making several phone calls to the transplantation nurses, whom felt so close to, to get some attention from them and hopefully also from the rest of the medical team. Moa’s need for attention seemed to have put quite a lot of strain on the nurses and their already tight schedule. The matter was regularly discussed during the HeartMate-meetings and transplantation rounds where the cardiologists found Moa’s need for attention blown out of proportion and medically completely unwarranted. After a couple of days of formal (meetings) and informal (hospital corridors, and the coffee room) discussion among the staff, Moa was called in for a talk with two cardiologists. The objective was to get Moa to realize that the attention she kept demanding from the medical team is something they cannot give her – something she must seek elsewhere.

Doubting their own abilities to take charge of their lives, patients cling to the only source of hope they know – the medical embrace. Mechanical devices spinning at tens of thousands of revolutions per minute inside their chests, that once were, and to a great extent still are, regarded as their only hope, turn, when out of reach of medical supervision, into potential bombs, ready to go off – a constant and inescapable threat to their lives. Thus, released patients are not merely torn between the two different sociocultural worlds, but also between these two contradictory qualities inherent in their mechanical help-hearts – a hope/despair paradox which they now embody. Even for those who qualify and make it through the subsequent heart transplantation, the long-awaited relief doesn’t seem to come while the threat of death remains.

In the meantime, while patients cling to the medical embrace for comfort and hope, the scope of this embrace, i.e. the attention granted from the hospital, is strictly limited to physiological concerns only. This is why the stage of reintegration is usually experienced as painful and anxiety-provoking. Moreover, patients no longer hospitalized express their concerns about not being understood by their new surroundings, where they are increasingly being challenged to legitimize their illness and to start taking responsibility for their lives. Unable to respond fully to the rules and norms of the world of the healthy, they are forced to negotiate for exemption from household and societal duties and, simultaneously, for consideration and understanding.

Involuntary patienthood

A fairly different way of perceiving this state of being caught in between two worlds was expressed by Niklas, a former mechanical help-heart patient. After the implantation Niklas dreaded the thought of proceeding with the treatment and getting a new heart. His hesitation had made him consider sticking to his mechanical help-heart for good. This particular story was one of many stories that were circulating throughout Heart Failure Ward during the time of my fieldwork. Niklas was doing so well with his mechanical help-heart that he felt that transplantation might just make things worse. In a way, this was yet another example of display of personal doubt concerning the future, perhaps even more extreme than those of Bengt-Erik and Maja, described in the previous chapter. After initially expressing his doubts about proceeding with the treatment, Niklas eventually came around and changed his mind about it. This is also when he realized that getting rid of his status as a patient won't be easy – one foot in his future, the other one stuck in his past. Nine months after the implantation of a mechanical help-heart Niklas received a new heart. The first time we met was during one of his annual check-up visits in Heartlands. The second time we met was at his home, where he told me his version of a story about a time when

he wasn't so sure about going through with explanting the machine and getting a real heart instead:

Niklas: ... I was doing so well, working half-time... it was almost as if I was over it now... I felt so good that I was considering keeping the mechanical help-heart... you see, I could understand the heart pump... that wasn't hard to grasp... I'd be cooled down and put on a heart-lung machine, they'd stop my heart and plug me in and get it on again... it was like, they had full control... A nightmare scenario was that I'd receive a call about a new heart... I'd get down to the hospital, the preparations are on... they go out to get the new heart and I'd go up for the operation... they would open me up, get my heart out and then somebody would stumble on the stairs with the bucket containing the heart... I was dreading that they'd open me up and take out my heart before the new one was there... that I'd, for even a briefest second, be really... really heartless... This thought took me a long time to get used to... get that... no heart... "I have no heart, no heart at all"... 'coz now it was really... everything needed to work... otherwise I'm finished... There were a great many thoughts of this kind of that I was having while waiting for a new heart... everything had gotten so fatal... at the same time, at the end, I started seeing before me... no more drive line... no more batteries, I can plunge into a lake and go for a swim... no more operations... I'm done with it, it's all over... and perhaps that also is having an effect on me when I feel as reluctant to have medical examinations and check-ups as I do.

(Excerpted and transcribed from audio recording, translated by author).

In contrast to Moa, whose improvement was rather slow and feeble, which made her cling to the medical embrace to retain the sense of hope, the velocity of Niklas' recovery made him instead fear and shun the hospital, the treatment that he was receiving, and the entire health care system. The medical embrace that in the midst of the treatment was his only source of hope (he considered keeping his mechanical help-heart) was, concurrently with his recovery, growing into its biggest threat and adding to the ambiguity of the embodied hope/despair paradox. Still, all mechanical help-heart patients are unsettled in this gap between two worlds. For those like Moa who remain ill in spite of getting better, their overt dependence combined with their loss of Heartisan status becomes unbearable. On the other hand, for the ones like Niklas, whose recovery rendered his patient status unnecessary, the life of repeated clinical examinations, tests, and treatments works as a constant reminder of their own vulnerability and the proximity of death. The closure he yearned for was not there for him to be had.

IV THE CLINIC

Niklas maintained that his condition had gotten so much better with the mechanical help-heart that he feared that the transplantation would just be a hazard to his improvement – a way to make things worse again. So he got to thinking about a life with a mechanical help-heart. At the same time, he complained about this inner struggle that he was having:

Niklas: Yes, I thought about sticking with the mechanical help-heart... but I was at the same time feeling well enough to feel restricted by it... not being able to

plunge into the sea... and things like that... so all of a sudden I realized that I've started building up a certain motivation to go through another operation... there was this positive drive... and still, when I got this phone call: "Hi, transplantation center calling! We've got a heart for you!", it felt like I was clubbed on the head... so I got my things together, I was like in a trance, I sat down in the back seat of the cab and wrote a goodbye note to the kids and to the ex-wife.

(Excerpted and transcribed from audio recording, translated by author)

As Niklas' story suggests, the better the patients feel, the more their attitude towards continuing regular medical check-ups, follow-ups, examinations, and tests seems to change. From being a source of safety and hope, they grow into a source of anxiety and ambiguity, or even a serious threat to their instilled sense of hope. The meaning of the medical embrace changes with the context. As the spatiotemporal variables are changing – space (from hospital to home) and time (increasing well-being over time) – so is the meaning that the clinic, doctors, and treatment have for the patient. Facing the reality of permanent patienthood, which remains fixed regardless of the patient's experience of well-being and progress, poses new challenges to his or her identity- and meaning-making. Neither quite healthy nor ill, they fall into a multifaceted category of ordinary people stuck inside the frame of an extraordinary clinical picture¹⁶⁴. The open-endedness of this situation resembles the ethnographic and phenomenological accounts of the experience of chronic illness and disability (Charmaz 1983; Murphy, et al. 1988; Murphy 1987; Toombs 1995). In contrast, Niklas's story suggests that what seems to be typical for mechanical help-heart patients is that the permanency of their patienthood comes with a sense of two-foldness which is enhanced by its inherent paradoxical character and also by the ever-

¹⁶⁴ See the account of Niklas below (pp 355-356).

present threat of death. In the face of adversity the stakes are high. In the face of uninvited death they're higher than ever before. And the paradox lies in the fact that the further away from the threat of death a patient gets, the more uncomfortable their patienthood becomes. The recovery that Niklas experienced relegated the threat of death. At the same time, the hospital, medical staff, familiar examination routines, and technology reminded him of the menace which he thought he had escaped. Due to his chronic dependence on continuous medical attention, wellbeing became a symbol of Niklas's own vulnerability – a marker signifying the threat of death and hope of life, simultaneously.

The first time we met in the waiting room during his annual check-up in Heartlands, Niklas said: "I don't like coming here at all... I feel fine and I'm afraid that they'll say something else". His feelings towards the health care system were additionally confirmed during our second encounter where he expressed his frustration about dependence on doctors and hospital rather explicitly.

Niklas: I'm feeling better now than I did before I fell ill... I was ill, got treated and now I've gotten better again... so I'm not stuck in this clinical picture but live my life even more intensely... and that's why I get more and more problems... you see, I react quite strongly to certain things.. and it's these encounters with health care that... eh, what can I say... all these encounters with health care... that revolve around check-ups, follow-ups, tests, and specimens... everything that in my paranoid mind aims at detecting some little disease in me... it's not the good levels that you wanna check but it's when the bad ones emerge... when a test result is too high or too low... that's what you're out to discover 'coz then you can do something about it... if the results are okay then everything is fine... so you look for what's

sick, what's deviant, what's worse... and I can't live my life that way... feeling as good as I do and living like that... I had to a degree... almost broken off relations with health care... I've put the period when I was ill behind me... and I don't mind talking about it with people who are not connected to the health care system... and on whom I don't depend as I am dependent on the Department of Cardiology in [Heartlands]... and I talk to others... friends, family and people I know... I have integrated this about being transplanted, having this experience, I'm alright with that... right now I'm healthy... this is the modern medical dilemma, that the task of a doctor is to take care of the sick person and to make him healthy... "So what do we do when we've made him healthy? Well, we make sure he's not completely healthy... but he needs to be checked and followed up!"... okay, I'm not completely healthy 'coz I need my medication but with my medication I'm completely healthy and can do just about anything, provided it's not bungee jumping, that's about the only thing that I feel I really had to give up...

(Excerpted and transcribed from audio recording, translated by author)

Niklas clearly expressed his discontent about this permanent contract for regular medical check-ups, follow-ups, examinations, and tests. He even suggested that, although it might be medically legitimized, he still felt that the very necessity and regularity of these hospital visits were being strongly contested by the fact that he doesn't feel any apparent need for them as he doesn't feel "stuck in this clinical picture". He referred to himself as healthy – but at the same time he reckons that healthy people are usually not subjected to such intense medical

surveillance. All that he gets from it is anxiety and, obviously, frustration at not being able to close this chapter of his life and move forward. This case shows how mechanical help-heart treatment was a success physiologically. Ritually (emotionally, socially, and culturally) however, it has failed. A treated person is expected to accept this new mode of existence as natural – a healthy patient or a sick non-patient, both embodying hope and despair and the oxymoron of the highly dependent kind of independence. For Niklas, this was hard to swallow. He wanted out! Ritual liminality, the inescapable state of a patient undergoing the treatment, is just not a suitable mode for life outside the hospital – a life outside the treatment. In Turner’s terms, a liminal world is the world upside down, the anti-structure, a make-believe, mocking mirror of the ordinary state of affairs. Therefore, a patient who is still in the liminal state is not suited for ordinary life. Or in Foucauldian terms, considering that the heterotopian nature of the hospital environment provides a shield of safety to its dwellers by being a secluded and purified place unlike the world outside, it follows (and is particularly evident in cases like Moa’s) that discharged patients, who are still emotionally, socially, and culturally depending on the shelter of this place, are like skinned bodies in harsh weather, bloated and defenseless.

CHECK-UP VISITS

A general overview of check-up visits bears a striking resemblance to the structure of separation practices already outlined in CHAPTER FOUR – SEPARATION:

3. **Diagnosis:**
 - a. anamnesis
 - b. physical examination
 - c. technological examination
4. **Selection:**
 - a. evaluation
 - b. discussion meetings

The first group of these already experienced practices that a patient reencounters during the check-ups consists of diagnostic practices – inspection of the patient’s current condition, its underlying causes, and the way it is progressing. Just as the practices of diagnosis that take place during the initiation into a mechanical help-heart treatment, the diagnostic practices during the check-ups are ordered in a sequence of three stages: i) anamnesis, ii) physical examination, and iii) technological examination. The second group of these practices is practices of selection – labeling of the patient with reference to the earlier established diagnosis (diagnostic classification) and the treatment that he or she had received¹⁶⁵, which is a foundation for further clinical discussions regarding the appropriate medical actions to be taken (further treatment selection). Selection is ordered in a sequence of two stages: i) evaluation (assessment and prognosis practices), and ii) discussion meetings (medical expert discussion practices).

The practical structure of check-up visits is strikingly reminiscent of the separation practices. However, there are a few significant qualitative differences between these two seemingly analogous groups of practices. During the separation practices, being in the midst of their ruthlessly ending lives, the patients seek hope and rescue in medical expertise and technology. During the check-up visits, patients seek the same medical expertise and technology – only this time not so much for rescue as for medical and technological maintenance of a medically and technologically gained hope. This maintenance is, however, inherently contradictory in that:

1. It repeats the structural practices of separation (diagnosis and selection) although these patients’ separation periods should be long gone and they should instead be reintegrated into their ordinary lives.

¹⁶⁵ For instance, they are usually referred to as “a mechanical help-heart patient” or as “a transplant patient”, and are in connection with each check-up visit discussed during the weekly Heart Assist Meetings and Transplantation Rounds.

2. The hope it seeks to maintain is defined by unending and routinized constructions of threat.

There seems to be a particular kind of tension inherent in each check-up visit. First, the reintegrating person is repeatedly being separated during each check-up. Furthermore, what is ultimately being checked for in these practices is what everyone fears the most. Expressing what he called a ‘modern medical dilemma’ Niklas posed a question: “... what do we do when we’ve made him healthy?” which he answered himself with, “... we make sure he’s not completely healthy... but he needs to be checked and followed up”. What Niklas seems to assert is that the check-up visits are where the threat, and hence the sense of dependency, are created and maintained.

The medical profession, Foucault asserts, is an institution of contradiction because it “seeks to destroy the very condition of its truth”, namely death (2006[1963]: 8-9). Niklas’ observation agrees with this argument Foucault was making about the irony of the medical profession. Similarly, while hope is medically and technologically maintained through regular check-up visits, this is done through the paradoxical maintenance of the very condition of hope, i.e. hopelessness generated by the imminence of certain death. Pragmatically, the aim of check-up visits is to reveal “what’s sick” and “what’s deviant” in order for doctors to stay one step ahead and keep control in reversing the course of things from negative to positive by pre-emptive actions. And yet, it is still a hunt on demise: risky, uncomfortable, and dubious.

SUMMARY

Analysis of ethnographic data shows that mechanical help-heart treatment, while saving lives, offers no way out of the ambiguity of its liminality. Life with a mechanical help-heart, regardless of whether it is arranged as a bridge to transplant or as a destination therapy, implies great adjustments in one’s mode of existence, completely reordering one’s daily life. A person needs to cope with the

exceptionally challenging requirements of the machine management and maintenance, being constantly dependent on a power supply system, and keeping track of the batteries. There are also various procedures for device tuning that need to be done. The patient must cope with uncertainty due to the pending risk of device failure or sudden unexpected physiological complications, such as infections. Furthermore, he or she must also deal with the requirements for unending compliance with prescribed drug treatments and life-style changes. This means that the person will have a lifetime of regular medical check-up visits and examinations and, for those surviving the subsequent heart transplantation, the new lifetime regime of immunosuppressive drugs.

Just as is the case with chronic illness in general, the fear from an undetermined worrisome present and future of a mechanical help-heart patient puts them 'on hold', i.e. trapped between the uncertainties of the present and the future until things get better and the patient can resume his or her past (Charmaz 1991: 33). Thus, being on hold is essentially temporary. However, instead of being temporary, the liminality of mechanical help-heart treatment is open-ended. This becomes most apparent at the stage of reintegration, the third and final stage of the mechanical help-heart treatment trajectory. In contrast to resuming his or her past self as described by Charmaz, mechanical help-heart patients are supposed to complete the transition into a new, saved self. Everything takes place, however, as if this new self remains on hold, caught between the conceptual boundaries of clinic/home, dying/living, hope/fear, safety/danger, and machine/body. Their open-ended liminality transforms the temporary into the permanent. Three components, which to a varying extent compose this new mode of existence, are identified:

1. Exposure – upon release from the hospital a patient loses the round-the-clock access to medical attention and care and therefore usually experiences unease and fear from being unprotected against many imminent threats.

2. Alienation – a patient usually finds societal life to be too demanding, obliging and lacking in understanding and sympathy towards his or her special situation.
3. Involuntary patienthood – regular check-ups and compliance to the medical regime is contested by the patient's recovery and increasing sense of well-being.

The new mode of existence is generated by the dualistic character of a patient's situation, as being caught between two worlds. Being still a patient, a person is not completely separated from the hospital. On the other hand, living at home, the person can no longer enjoy the full medical embrace of the hospital and is thus exposed to various threats. At the same time, while close ties with the clinic are being kept through regular check-up visits they provide both hope and fear at the same time. Furthermore, as the patient moves back home, the proximity to community life makes it exceptionally inviting and at the same time exceptionally unsympathetic – the sense of belonging is everywhere yet always somehow just out of reach.

What is most intriguing with this new mode of existence is that its dualism seems to bring the instilled sense of hope into doubt again. "I do what I can... but finally there is a limit to what I can do. I can only hope", maintains Crapanzano, asserting that hope presupposes certain metaphysics wherein it can be situated as a particular take on reality (2003: 6). So hope can be temporally specific in being directed towards a desired outcome of something that is about to happen, but it can also be temporally open-ended in that it welcomes something of which the occurrence is uncertain¹⁶⁶ (Ibid: 6). Due to the open-endedness of liminality in mechanical help-heart treatment, the hope of improvement, recovery, and reintegration that it offers is also open-ended. At the same time it is maintained by continuous symbolic perpetuation of imminent threats through regular check-up visits – the threats on which this particular hope is dependent. In other words, it is paradoxically perpetuated by its constant negation.

¹⁶⁶ As, for instance, Armageddon, the return of Christ etc.

When hoping as a form of passive action – “I do what I can... but finally there is a limit to what I can do. I can only hope” – gets contested, all that is left to do is to make construction and maintenance of hope the primary *modus operandi*. The routinized lifelong hunt for threats through regular check-up visits acknowledges and upholds these threats as essential dangers to be guarded against. Check-up visits as ritually performed social drama of hoping seem to help escape the passivity of “I can only hope” and ensure a more active practice of hoping that is more in harmony with the Western concepts of progress, achievement and success (Crapanzano 2003: 19; Mumford 1986; Nisbet 1980; von Wright 1993). Thus, hope becomes the never-ending project to be worked on. Instead of coming to an end, the mechanical help-heart treatment seems to be locked in a loop.

PART III

PART III is the final part of this thesis and is composed of one concluding chapter, CHAPTER SEVEN – DISCUSSION, that provides a summary and a discussion against the backdrop of preceding empirical chapters. I also make some more general remarks based on these findings and address some related topics of more broad-spectrum character: global nexus of technology research and development, the Medical Industrial Complex (MIC), the concept of progress, etc. Finally, I draw some conclusions and connect them to the idea of progress in Western cultural heritage by discussing the ways in which this concept is embodied through the practices of implanting mechanical help-hearts.

CHAPTER SEVEN – DISCUSSION

I

THE HEART TOMORROW

In this thesis I have explored ethnographically the circumstances under which new medical technology is becoming a standardized part of biomedical treatments of end-stage heart failure, and looked at what cultural norms, values, and moral codes are related to such circumstances and in what ways. I asked how the ways in which the mechanical help-heart treatment is performed in Heartlands tie into Heartisan ways of knowing and feeling. I have also explored how local understandings of life-threatening chronic illness, the body, and the role of medical technology are shaped through institutionalized and ritualized biomedical practices. Furthermore, I also asked how the participants understand and negotiate the effects that the mechanical help-heart treatment has.

On the whole, the research shows that the standardized and structured ways in which these particular treatments are performed assemble participants into the collective management of individual suffering – and thereby also into the joint enforcement of particular cultural understandings. It is upon these understandings that the procedures are built. Hence, besides being simply instrumental, these practices also ritually express the cultural understandings upon which they are built. Furthermore, in addition to providing a way of dealing with end-stage heart failure, these practices also help medical professionals and sick persons make sense of their situations and to endorse their agreed-upon ways of dealing with it.

Above all, the ritualized ways in which Heartisan doctors and nurses approach the human body, illness, and technology reflect their take on the world as essentially factual and on knowledge as essentially built on traceable evidence, enabled by natural science. Anything that falls (or is thrown) outside the categories of ‘facts’ and

‘evidence’ brings indeterminacy, and thus also confusion, into the equation of their logic. Hence, such elements are either shunned if possible, or dressed in familiar and biomedically sound attributes if not. This way they are shaped to fit the Heartisan logical picture. Sometimes, this might lead them to leap over a few gaps in reasoning – making leaps of faith, necessary in surmounting the obstacles of indeterminacy. Most times it renders the power of rituals – understood as carefully thought-through and formalized practices – the only shield against the dangers of indeterminacy. Heartisan patients are systematically socialized into this way of understanding and are, hence, integrated into the Heartisan culture.

Talking about leaps of faith in the context of evidence-based medicine is not free of risks. Still, as the case of mechanical help-heart treatment shows, certain clinical practices exceed the limits posed by the knowledge upon which they rest. This book provides an insight into the ways in which such practices are structured so as to ensure their instrumental potency in spite of these inherent uncertainties. Nevertheless, besides functioning as a safeguard against the perils of indeterminacy, these ritualized forms of conduct also: a) legitimize the practices before their own cultural underpinnings (consisting of strict norms, values, and principles of evidence-based medicine); and b) influence the ways in which life-threatening chronic illness, the body, and medical knowledge and technology are understood.

THE HOPE

Analysis of the collected ethnographic data shows that hope is an essential element of modern medical care for patients suffering from end-stage heart failure and is central to at least two aspects of these practices. First, the process of creation and maintenance of hope is an important part of the medical professionals’ way of helping their patients to deal with the uncertainty of their illness. Second, creation and maintenance of the sense of hope also helps the medical professionals’ dealing with uncertainty in their risky business. In other

words, hope makes their work meaningful, thus also reinforces their sense of professional identity.

The sense of hope, primarily as a virtue, is one of the main sensibilities of the mechanical help-heart treatment, of the sick persons' initial interactions with the society outside the hospital, and also of the medical professional's efforts to make sense of their work. Hope is, thus, the main property of these new cultural forms that are embodied through the mechanical help-heart treatment. Cultural forms are, according to Turner (1997[1969]), the culturally specific myths, symbols, rituals, philosophical systems, and works of art, that are tied to, or generated in, certain conditions such as severe illness. Not only do these cultural forms provide people with classificatory models for understanding their relationships to society, nature, and culture, Turner states, but they also move people deeply, inciting them to both thought and to action (Ibid: 128). Desjarlais also emphasizes the importance of culturally specific styles in which people structure and design their everyday life – such as ritual, architecture, or styles of storytelling – as highly influential on the ways in which they understand themselves and their being in the world (1992: 39). Inherent to the structure and design of these cultural forms are people's deeply felt understandings – “felt sensibilities” – of the multileveled context to which they relate (Ibid: 248). In the case of the mechanical help-heart implantation treatment, this context is made up of people's understandings of what is at stake, of the surrounding social/structural conditions, and of the ontological fundament (or what Turner calls philosophical systems)¹⁶⁷ wherein these practices are situated. Here, hope is a strategy for the success of the treatment. Nevertheless, according to my study, hope is also much more than that. Hope is the ultimate goal, embedded into the expectations of the future that can be brought about through progress

¹⁶⁷ By the ‘ontological fundament’ or ‘philosophical systems’, I refer here to the generally shared understanding in a certain culture about the ‘order of things’ with all its tacit moral codes, norms and values. In the case of mechanical help-heart treatment these moral codes, norms, and values are tied to our understandings of the body, illness, health, life, death, technology etc.

of medicine and technology. Both the idea and the sense of hope are carefully and systematically created and maintained through mechanical help-heart treatment in accordance with these biomedical expectations of the future. Hence, hope is enacted as one of the most important principles of biomedicine. Ultimately, this is what makes hope an inherent element of the authority of science and technology, and thus also a virtue.

The formalized, instrumental, and communicative dimensions of these practices render them as rituals through which hope is obtained and maintained – hope rites. It is through these practices, which are strongly linked to concepts of life-saving and restoring, that hope is enacted. Everything takes place as if this particular hope is forged by the tension between two polarities: 1) *life crisis* (the class of phenomena that stand in the way of the life continuity – in this case a life-threatening chronic illness), and 2) *progress* (the class of phenomena that demands life continuity – in this case belief in progress through continuous advancement of medical technology, supremacy of medical knowledge, and skills and experience of medical professionals, promises of device manufacturers, justifying success-stories about victorious survivors and other similar sensational stories, and the idea of ‘future appropriations’¹⁶⁸). These are the key symbols of biomedicine’s “progress against death” (Ortner 1973; Plough 1986: 4). Through their ritual enactments a sense of hope is created and maintained even when the prosperity of future appropriations is seriously threatened. In the meantime, hope mediates between the two, i.e. between *life crisis* and *progress*, providing them both with vigor and meaning.

These particular practices express a special kind of values and sensibilities in relation to the threat of death, afflicted bodies, and belief in the power of medical technology and knowledge. It is through the bodily enactment – through the ritual performance – that these values and sensibilities are embodied. The story about end-stage heart failure and mechanical help-heart treatment, as it is portrayed in

¹⁶⁸ See pp 45, 52.

this thesis, is primarily a story about the performed ritualized social drama taking place between a severe life crisis of the grip of death and salvation that lies in the promise of technological progress. To illustrate the dynamics of this drama, I will use here a simplified abstraction and analysis of its three main elements: life crisis, hope, and progress (Figure 40).

Life crisis brought by end-stage heart failure is understood as a danger to future appropriations and is therefore a threat to a culturally valued continuity. The severe chronic illness of end-stage heart failure is thus understood as: i) a menace to the sick individual as well as to the community and society in general¹⁶⁹, ii) a failure of the body to live up to its cultural expectations (well-being and longevity), iii) a threat to the sick person's identity, and iv) a disruption or disorder in what is culturally considered the normal course of things (continuity).

Progress, recognized above all in the steady stream of new life-saving medical technologies, surfaces as the somewhat altered or reinterpreted reincarnation of the ancient idea of panacea – that “infinitely remote corner of nature” where all the antidotes to any sickness or disease in the world are to be found (Foucault 2006[1972]: 300). It seems as if this corner of nature lies in a just as infinitely proximate corner of the future – hence the modern cultural obsession with the future.

Hope, created and maintained through routinized practices of a mechanical help-heart treatment, which I call the hope rites, brings disorder into order and provides an escape from the grip of death by offering glimpses of these desired corners of the future to be colonized. Hope gives a chance of continuity and instills the sense of opportunity, promise of salvation, and something to believe in. That's why hope in Heartlands enjoys a status of a virtue.

Together, these three elements of hope rites make up the *crisis-progress-hope* triad, indispensable in making mechanical help-heart treatment possible. On the other hand, while being essential to

¹⁶⁹ Heart failure is not only an individual concern but is also, due to its proportions, a public health problem.

mechanical help-heart treatment, hope also makes up the core of the dominant biomedical discourse about the sick bodies, death, and new technology. Considering its importance in biomedical attempts to alleviate human suffering caused by severe illnesses, the power of hope seems to belong to the morality inherent to it. As a morally loaded attitude, hope in mechanical help-heart treatment is just as fascinating as it is contractual or obligatory. At the same time, things so awe-inspiring and engaging are also very easily commodified and utilized for various purposes. Therefore, we must not forget that hope, besides helping people, also enables the techno-markets to operate – not merely to function but also to be very lucrative. Therefore, it is of great importance that these forces are not merely unleashed, but that they, instead, are at all times audited from a critical cultural perspective.



Figure 40: The *crisis-progress-hope* triad.

Paradoxically, in spite of the fact that hope inherent to mechanical help-heart treatment might at first surface as a specific emotional state, patients' emotions in general are reduced to the physiological workings of their bodies through the formalized ways in which their treatment is structured and performed. Thus the hope, conceptualized through the power of the miracle of progress, is

formed through these practices, not as a sensible existential element of a person or a group but rather as a virtue or morality in light of which the authority of medical technology and knowledge is rendered nearly undisputable. Through a mechanical help-heart treatment, this new cultural form – the hope invested by reason into the belief in medical/technological progress – is embodied into the bodies of ill persons. In other words, bodies, while being kept alive, are also upgraded to the current pace of progress. This way they are made to fit into the scientific and technological imaginaries of biomedical engineers and doctors and also those of MIC company executives.

This study shows that the ways in which mechanical help-heart treatment is structured and enacted is an expression of a biomedical paradigm describing the life-threatening chronic illness, the human body, and technology in terms of measurable facts of natural sciences while downplaying their social, cultural, and emotional aspects. Furthermore, by expressing the large-scale biomedical ideas on which they are based and which they reinforce, these practices rest on the sense of hope to also express and reinforce the neoliberal Western ideas of progress and beliefs in the power of medical science and technology.

Open-ended liminality

Even when the treatment is regarded as successful, another challenge remains. Namely, these patients might be saved but are never really 'cured'. Thus, they remain permanently tied to the world of medicine – a mode of existence that they must learn to live with. This mode of existence is characterized by the paradox of permanent transit between two worlds, between nostalgia towards the healthy past and dreams about the healthy future, between uncertainty and hope (both inherent in the treatment at the same time), and between nearly-escaped illness and almost-achieved health. Initially, sick persons make sense of their situations and of themselves with the help of rites of separation, through which they enter the world of Heartisans where their individual suffering is made into a collective concern.

Their identities are, during this phase of the treatment, temporarily altered for the integration into Heartisan community. They are first socialized into their new patient identities and are integrated into Heartisan society, leaving their normal lives behind them. Throughout the whole treatment, the patients are reduced to their physiological bodily functions – a necessity which makes the treatment doable.

To avoid misunderstanding I wish to make clear that this observation does not imply that the Heartisans' clinical work is cold or inhumane. Nor does it mean that it is devoid of empathy and compassion. I have no reason to believe that assistant nurses, nurses, and doctors in Heartlands are not caring, protective, and very considerate of their patients. If anything, it is safe to say that they do their work with a great deal of dedication and passion. Nevertheless, throughout the entire course of mechanical help-heart treatment, the felt experience is defined and organized in terms of biomedical epistemological and ontological grounds, based on the natural scientific paradigm. What appears as a contradiction here is more a matter of finely drawn nuances; it is possible that individual care-givers can be quite attentive, sympathetic, and warm, but the rigid structure of their formalized practices limits such qualities. This means that the ways in which the clinical practices are structured and organized do not provide even the most attentive and sympathetic of the care-givers with enough action space for paying attention to the non-physiological dimensions of a patient's illness. Moreover, the fact that the individual patients seek comfort, relief, and hope in being treated by the collective, i.e. the Heartisans, does not mean that the collective directs any special attention towards the social, cultural, and emotional aspects of a patient's illness. This study shows that the symbolism of collective attention and care is necessary, yet not sufficient, as the treatment still rests on the view of the body as a conglomerate of physiological processes. This is why the unattended dimensions of patients' illness – such as the changing preconditions of their social relations, their contested views about their being in the world (patient/non-patient, sick/healthy, etc), and their deeply felt

fears, worries, etc. – tend to collide with their everyday lives after they leave the hospital.

This means that much of the non-physiological aspects of a patient's illness that are hidden during the limbo of liminality also remain hidden throughout the whole treatment. Consequently, upon the patients' reintegration into society, these aspects still remain unattended by medical science, resulting in their social invisibility. Instead of being reintegrated, patients seem to end up in a blind spot of society. Nevertheless, the sense of hope needs to be maintained. This is done through regular medical check-ups and drug regimes. In the meanwhile, their social displacement stirs up their deepest existential foundations – they are neither sick nor healthy, neither dying nor cured, neither regular members of the community nor patients. As their liminality is not successfully brought to a closure their ritual transition to reintegration has reached a cul-de-sac.

In general, doctors and nurses in Heartlands use and speak about modern heart technology in the manner and language of hope. Often, they express professional pride in the technology. This pride is at least partially grounded in the fact that they are the ones who know how to handle and interpret this technology. Thus, by performing these high-tech practices they display their own mastery of it. This, in turn, serves as evidence of clinical expertise, thus generating and upholding the sense of hope. Much of this technology sheds some light on the unknown – as for instance the inner workings and states of human bodies. As it provides medical professionals with the power to see what otherwise cannot be seen, the technology serves to keep the hope about achievable repairs alive. So mechanical help-heart treatment brings about hope and is in Heartlands regarded as powerful and indispensable¹⁷⁰. However, the hope that is being

¹⁷⁰ It should be noted here that not all Heartisans agree about the high status that the mechanical help-heart treatment enjoys in Heartlands. One of the cardiologists, who today is no longer part of a HeartMate-team, told me on one occasion that the money invested in very expensive mechanical help-heart treatments would do more good if used in the primary care, with the aim of

generated here is tied to medically imagined future appropriations and achievements available through the power of technological progress and knowledge. Rather than being conveyed and adhered to as an individual emotion, the hope is enacted as a virtue and a necessity, i.e. a norm to be respected and internalized as culturally-approved posture towards the life.

On the whole, this technology is to a great extent spoken about and treated as hope, in a sense of “the patient’s only choice” or “the patient’s only chance”. In the meanwhile, as it is readily ascribed the quality of a heroic life-saver, the outcome of the mechanical help-heart treatment is contested. On the one hand, patients’ lives are saved and the symptoms of their heart failure are reduced. On the other hand their role in society remains ambiguous.

MAKING A DIFFERENCE

To say that people in Heartlands embody new cultural forms (see pp 379) through ritualized clinical practices is not to say that they are prisoners of normative structure, simply reproducing its regulatory schemes, discourses, and infrastructures. While they through these practices undeniably learn about and are influenced by this structure, each practice still provides enough headroom for what Mattingly (2010) calls, “less visible tactics” to take place. While enacting formalized and strictly regulated practices, they still also struggle, manage, and cope with real-life situations, bodily pains, clogged vessels, wayward machines, and a myriad of other unpredictables of life. Herein lies the possibility for change, for making a difference. This is why problems get solved and lives get saved. This is how lived hardships are translated into embodied knowledge, tactics of enduring into legacy to be passed forward, and clinical trials into medical innovations. Modern medical technology and knowledge make

detecting and preventing the progression of heart failure in patients earlier in its development.

people's lives longer and often they make people's suffering less painful to cope with. Ultimately, they provide meaning and hope when there is none.

People who suffer from severe end-stage heart failure turn to Heartisans for help. Something needs to be done about their condition and Heartisans are generally regarded as having the right knowledge and technology for these purposes. Moreover, not only are illnesses attended to through these practices, but personal sufferings are made into a social matter. Hence, by making personal problems such as misfortunes of deadly chronic illnesses into a collective concern, these practices help distribute the burden of suffering. The afflicted individual and/or family are no longer alone.

Far from merely reproducing the society, these practices make up the most dynamic part of large-scale social and political forces, responsible for continuously breaking new paths. Each innovation, each new medical miracle, opens up new fields of practices¹⁷¹. This, in turn, is where established local worldviews get reconfigured in accordance with the particular set of dominant understandings upon which these practices rest. These understandings are transnational in that they are suspended in the global standards of biomedicine and bioengineering. They have been called medical imaginaries and are the driving force of medical science, the Medical Industrial Complex, and the political and moral economy tied to them. This study shows that people suffering from serious illnesses, such as end-stage heart failure, are especially susceptible to the influence and promises of these medical imaginaries. The medical imaginaries are forged in the intersection between bioengineering and experimental clinical practice such as implantation of mechanical help-hearts. As such, they are a great force empowering medical scientists' and engineers' daring attempts to colonize the future.

¹⁷¹ For further discussion on large-scale sociocultural aspects of mechanical help-heart treatment see Collective Liminality section below (pp 401)

III CONTRIBUTION OF THIS THESIS

THEORETICAL CONTRIBUTION

Ritual and belief

This thesis is primarily based on an ethnographic study of a particular kind of practice. What's so special about this particular practice is that it shows some interesting examples of organized and institutionalized ways in which people use new medical technology to deal with severe illness and threat of death. These particular ways are increasingly gaining acceptance throughout the world as they have come to represent reason, knowledge, and good sense. Moreover, the practice's distinctiveness lies in the fact that people seek inspiration and guidance for these actions in the realm of the future (medical imaginary, progress, technological development, hope) instead of tradition. This renders these practices modern and hence highly popular in the bulk of the public discourse and also among people in general. This is why it is often referred to in a language of awe and devotion.

By analyzing the details of the ways in which these practices are conducted I have aimed at understanding the (ideo)logical structures upon which they rest. The ways in which we organize and conduct these collective actions depend on the meaning we have culturally ascribed to them. At the same time, what meanings we ascribe to these practices depend on the ways in which we organize and conduct them. As I have demonstrated throughout this thesis, the more formalized our practices are, the more important they seem to become. Thus, we approach them with a sense of reverence and respect. This is what makes them ritual. Moreover, I have also aimed to show how regarding a practice as a rite is far from degrading it to a merely symbolical and irrational act. Therefore I argue that ritual studies provide a very useful analytical key in our attempts to understand any kind of more or less formalized practices that people

who instigate and/or perform them consider as momentous enough to be performed at all, if not unavoidable.

Mechanical help-heart implantation rituals reveal a wholehearted engagement amongst the Heartisans in which a rigid structure of performance is endowed with the dynamics of passion, belief, trust, and hope. Yet this dynamo mirrors more a culturally predetermined set of categories upon which these practices are built and which they also aspire to than it provides free headroom for reflection and/or expression of spontaneous emotions or emotional states. In other words, any impulsive, unstructured, uncalled-for, or hard-to-handle emotional response is regarded as emotional deviation, which is a hazard to the treatment. The emotional response is treated accordingly by being suppressed, negated, and bracketed as improper and insignificant. The culturally distinguishable sensibility that is typical for the people of the Heartlands is thus continuously being generated and maintained through these practices. At the same time, as it is suspended in a translocal network of various groups of people, from bioengineers, scientists, medical doctors, and patients to investment vendors, advertisement teams, lawyers, and politicians, it is also part and parcel of a cultural milieu that is much wider than the walls of the Heartlands. Some of the most central pillars of this vast cultural field are reflected in the Heartisans' performance of mechanical help-heart implantation, particularly in the expected reverence and devotion towards the powers of medical and technological progress. The fact that these particular kinds of belief, reverence, and respect, however, are not religious seems to clash with the assumptions about the differences between science (reason) and religion (belief) that are widely accepted in the Western world. These assumptions have also been very influential for the ways in which ritual theory has been developed over the years.

I follow the lead of my ethnographic evidence and suggest that ritual theory needs to be freed from the authoritative concepts of 'religion' and 'belief' as determinants of what counts as ritual and what does not. This way, at least some of the confusion caused by the

often sloppy usage of these concepts might be avoided. Medical rituals observed in Heartlands are widely recognized as non-religious, secular, scientific evidence-based practices. Yet the fact remains that there is a strong element of veneration surrounding the Heartisans' views on things like technology as a manifestation of cutting-edge medicine, or on medicine as a natural and objective science. Moreover, the insights brought by clinical trials and the power of genuine clinical experience are also viewed in this fashion.

Heartlands practices are permeated by dimensions of being human that fall outside the frames of formal medical knowledge. Such dimensions are evident in the fact that there are no warranties of success in any offered treatment. The uncertainty of success and probability of failure inherent to the mechanical help-heart treatment, combined with the fact that real human lives are at stake, render this practice particularly vulnerable. Consequently, the logic with which Heartisans attribute meaning to such uncertain practices allows for certain leaps of faith to compensate for logical fallacies when necessary. The words of a doctor quoted earlier in this book¹⁷²: "It's not a matter of belief... I know that it so!", capture very visibly the Heartisans' general negative attitude towards the idea of faith or belief. Yet a statement so resolute seems to require at least a little bit of sheer belief (as a form of confidence in the criteria which make this knowledge so certain) in order to be stated at all – belief in principles and workings of natural laws, belief in the significance of clinical trials and biomedical experiments, belief in the accuracy of medical science and the effectiveness of medical practice and, finally, belief in medical technology¹⁷³.

The culturally shaped emotional ties to the concept of progress that are being enforced through these practices are strengthened and maintained in the tension between life crisis and hope – whatever

¹⁷² As he was discussing a patient's condition with the patient (see page 228)

¹⁷³ Just as this study is enabled by my belief in the power of anthropological knowledge about healing rituals and in principles and accuracy of ethnographic methods of data collection and analysis.

dread and discomfort is caused by the former is believed to be counterbalanced by the power of the latter. Moreover, the sense of hope is defined and legitimized through the occurrence of life crisis – and vice versa. Yet in the case of end-stage heart failure, this relationship between life crisis and hope would probably not be possible if it wasn't for the power of progress. Progress thus makes hope possible for the hopeless people. This progress is tangibly manifested in mechanical devices which literally give hope its concrete physical shape. Each mechanical help-heart is therefore a reification of hope, a mighty life-saver worthy of reverence and respect. The momentousness of mechanical help-heart implantation treatment is evident in the ways in which Heartisans tie the sense of hope, trust, and significance to these practices.

This thesis provides a critical examination and discussion of this cultural self-knowledge. The widespread view of the world as divided into secular and religious fails to acknowledge the situational, highly dynamic, and multiplex character of things, as for instance the occasions when what is recognized as secular science and technology are consecrated through practices and discourses of unconcealed devotion to science and technology, a total investment of hope in science and technology and/or unrestrained reverence of their all-encompassing significance. Therefore, the secular and the religious, as well as the belief should, instead of being regarded as the determinant criteria for study of ritual practices, be considered as possible empirical findings the role and nature of which should always be considered in a context of their appearance. Their meaning is, after all, always culture-bound.

Embodying New Forms

Through the liminality of mechanical help-heart treatments, the patients are introduced to a whole new set of “cultural forms”, as Turner would call the myths, symbols, rituals, outlooks, and artifacts frequently generated in such events (1997[1969]: 128). Through the sentiments expressed in heart myths (success-stories, horror-stories,

stories of disobedience, etc.) as well as through the meanings attached to the hospital, the white coats, blue scrubs, green scrubs, stethoscopes, scalpels, various diagrams, echocardiographs, X-ray and ultra-sound images, pharmaceuticals¹⁷⁴, CT-scans, mechanical help-hearts, human hearts¹⁷⁵, vessels¹⁷⁶, and entire bodies, the authority of biomedical power-knowledge is consolidated and its ontological grounds rehearsed and legitimized. Consequently, through the standardized ways in which these new forms are being enacted, the human body is systematically *done* as abstract nosological categories, tangible organs and tissues, and observable and measurable physiological workings.

Regarding Turner's usage of concept of "cultural forms", Maynard's (2006) observations discussed earlier (pp 45, 51) provide a rather interesting perspective¹⁷⁷ from which mechanical help-heart treatments can be discussed. Maynard refers to organ transplantation as a *new form of embodiment* meaning that these practices provide new ways of individuals' self-adjustment in tune with the harmony of society's chord progression (Ibid: 277). In light of this, if transplantation (of harvested human organs) is regarded as a *new form of embodiment*, as Maynard suggests, then the implantation (of machines) can be viewed as the *embodiment of new forms*, i.e. embodiment of new cultural systems of meaning and consequently also of new modes of existence. While transplantation helps in prolonging the biological continuity of life, the implanting of mechanical machines can upgrade not only the body, but also the very same biological continuity of individual's life with cultural dimension,

¹⁷⁴ Often referred to by one of the cardiologists as splices.

¹⁷⁵ Described as tired/vital, weak/strong, good/bad, dispensable/indispensable, a muscle, a pump, etc.

¹⁷⁶ During one of the two mechanical help-heart implantation surgeries I watched, the anesthesiologist on duty looked at the ultra-sound image of the patient's vena cava and called it "a hose" several times, in attempts to ironically calling attention to its unusual size.

¹⁷⁷ Although it bears strong resemblance to Foucault's notion of subjectivity and self-monitoring.

wherein a fragment of anticipated future is actualized through upgrading and technologization of the body, pushing our expectations one step beyond the point they recently occupied. Thus, incarnating life-saving machines means embodying cultural expectations of future. No longer merely used to alleviate the burden of disease and defy death, this new technology is now literally inserted into the very core of our beings, bearing concrete materialized witness to its own necessity as a precondition of life itself. Note that only a fragment of desired future is been actualized, while the large part of it remains indefinitely unknown and puzzling, (Thrift 2006: 192). This makes human body a never-ending project.

Focusing on these standardized practices in which people implant machines as a way of dealing with their life-threatening illnesses will, I believe, bring us closer to the meanings attached to these machines, and to their influence on the continuous processes of carving out the cultural categories of life/death, body/machine, and self/other for those concerned. These issues are, in my opinion, of considerable importance for our understanding of relationship between humans and modern technology. This study shows that this relationship is on the whole fairly paradoxical; on the one hand it is often overwhelming and awe-inspiring, but on the other hand it is rather binding, very strict and formal, demanding, and built on the foundation of the state of dependence. Here, our devotion, loyalty, and allegiance to our machines, and also to the idea of progress which they, through the consecrated practices that surround them, come to stand for, appear as a debt or a contract. In this day and age when the bond between humans and technology is stronger than ever before as it opens up new levels of our co-evolution, the technology can no longer be reduced to merely an extension and amplifier of human expertise. Instead, it emerges as an actor in its own right, potent enough to bring about profound changes in our world views, our practices, our roles, and our expectations of the future.

The relationship between the individual and the society is managed through the ways in which the body is institutionally

configured through formalized cyclic performances. In mechanical help-heart treatment, actual human bodies, bodies of doctors, nurses and patients, engage in practices through which new cultural forms packed with symbols and sensibilities carrying particular norms and values are embodied into the participants' systems of dispositions for thought and action¹⁷⁸. These cultural forms include styles of building and organizing the space of hospitals, telling stories about the heart, the body, life/death, health/illness, organizing work, using (and talking about) cutting-edge medical technology, performing surgery, etc. The institutionalized embodying of norms through ritualized practices determines *what* and, perhaps even more important, *who* fits into the biomedically established ways of knowing and feeling and what/who doesn't.

Everything takes place as if people, instead of ascribing the state of embodiment (noun) as something that is imposed upon them, are

¹⁷⁸ This discussion borders on the Foucauldian concepts of gaze, discipline, and body politic as well as on the Bourdieuan concept of habitus. As this dissertation discusses human body, medicine and routinized, habitual, medical practices, I believe that these particular notions would be helpful in pushing the final analysis and discussion a bit further. 'Gaze' is a term that Foucault uses to describe: a) physician's power to see through the 'what *appears*' and reveal the 'what *is*', i.e. to see the hidden truth; and also b) the normative power exercised by the general authority of the postulates of biomedical science, constructing the compliant subjectivities (Foucault 2006[1963]). 'Habitus', on the other hand, is a term that Bourdieu uses to describe personhood as embodied social and practical self (Bourdieu 1977). It is easy to see how these two theoretical approaches are linked to one another: whereas Foucault looks at the human body through the lens of power of normative structures and discourses, Bourdieu looks at it through the lens of the actual enactment of these structures and discourses – enactment through which they are simultaneously being embodied and (re)constructed. There is no doubt that the present discussion would benefit greatly from venturing into their teachings. However, I choose to leave this to be discussed elsewhere due to the limited scope of this thesis.

actively embodying (verb) the world around them, thus confirming the suggestion that bodies and practices are mutually constructive (Bell 2008). People create their worlds while and by being active in them. People act, and they act the same and differently, a lot and a little, and, most important, people act together with more than themselves. Practices are by and large intersubjective as they take place among people. People handle the circumstances. They manage. People create the phenomena in and through their practices. They manage the existence that shapes them. Ultimately, people run things and things run them, reciprocally.

The ethnographic evidence presented in this thesis shows that ritualized clinical practices are practical manifestations of dominant biomedical ways of knowing and feeling as they bring the future into being. By doing so, they add more power to the growing authority of biomedical understandings. Similarly to Turner's analysis of sacred liminality amongst the Ndembu, the understandings that are conveyed in mechanical help-heart treatment – its revered status as the only hope and its potent power – is not just a sum of the uttered words and tasks done. They have what Rappaport (1999) refers to as “canonical”, or Turner (1997[1969]) as “ontological”, value. In other words, they modify the very being of the patient. Just as the Kanongesha “has come to be born into chieftainship” so has a HeartMate-patient come to be born back into his or her life, embracing the pillars of modern biomedicine and technology as the very impetus and precondition of life.

As the human body is, besides being a conglomeration of physiologically interdependent biological components, also a concrete place of perception, the practices people engage in are sedimented as embodied experience. While ritualized practices make up a constant series of performed social dramas, each time they are performed the cultural systems of meaning (or webs of significance) on which they rest are rehearsed. Hence, these dramas are also to be understood as rehearsals. As such, each rehearsal works in two ways. First, it helps to reinforce the same systems of meaning on which it rests. Second, it

allows for unpredictables, blunders, practical limitations or insufficiencies or any other kinds of undesired and/or unanticipated effects of these practices to become visible, thus enabling the change to take place. This means that the particular ways in which these practices are (per)formed have a particular influence on the shape and content of the sedimented embodied experience. Consequently, as the structure of hope rites upholds the non-physiological aspects of illness and renders the measurable medical facts as the only facts that are relevant, these principles are also embodied by the participants each time they participate in this ritual. One example of this sedimentation is captured by Physiotherapist Lea's observation, quoted earlier, which is worth repeating: "As soon as they [HeartMate-patients] get transplanted they also lose all that attention they have been receiving during their time with HeartMate®. This usually results in their feeling low-spirited, even depressed, and feeling abandoned and alone".

The technological "mechanical help-heart" innovation is in this process transformed into the active constituent of the human body at the same time as the human body, in all its functionality, is depicted as a machine. End-stage heart failure patients are bestowed with hope through biomedical hope rites, but also with open-ended liminal ambiguity. This is because they take place in the betwixt-and-between corridors of human existence, i.e. in the borderlands between some of the most fundamental conceptual dualisms, where what it means to be human is continually being (re)hammered out: sick/cured, body/machine, hospital/home, culture/nature, life/death, to name a few (Douglas 2001 [1966]; Haraway 1991). Hence, clinical treatments of end-stage heart failure pose serious challenges to any kind of categorization. Nevertheless, if we assume that any framing and organizing of experience in accordance with certain established conceptual classificatory systems and canonical patterns of beliefs requires a set of relatively well-defined categories (Bruner 2000[1990]: 56), then mechanical help-heart treatments seem to introduce the realms of humanity that are the property of in-between, which in the

world of frames means the property of nowhere. This leads us beyond the structuralist ideas of conceptual classificatory system as being the elementary organizer of our cultural worldviews, and even beyond post-structuralist notions of these conceptions as constituting a platform for the fabrication of justified inequality, i.e. acceptance and glorification of domination. The biomedical ritual integration of body and machine, nature and culture, illness and health forces the course of the illness itinerary of end-stage heart failure through the lands of in-between. Deprived of their recognizable cultural directional signs and obstructed in organizing their experience, mechanical help-heart patients learn to roam deframed in the world of frames.

METHODOLOGICAL CONTRIBUTION

A chameleon of participant observation

Along with globalization and the rising complexity of human existence that it brings, the fields of anthropological enquiries are becoming increasingly translocal and multiple. Once again, anthropological scientific binoculars need to be adjusted to fit these quickly shifting conditions. This research is based primarily on participant observation amongst the Heartisans of Heartlands. However, the translocal nature of the mechanical-help heart treatment required some broader contextualization. So the ethnographic data that was collected through participant observation from a particular local site was complemented with a variety of data, collected from multiple sources, with the help of a mixture of different techniques.

Given the fact that I had to negotiate with gatekeepers about my access to the field for a whole nine months, and also considering my continuous and disconcerting struggle against the power-plays in Heartlands to enforce the given permission to conduct my participant observations, this choice of method was obviously a risky one. Still, I couldn't see how any other of the conventional qualitative research techniques, such as interviews, focus groups, or document and/or

discourse analysis, could bring me as close to understanding the practical world of mechanical help-heart treatment as I believed participant observation can. Only by participating in and observing the Heartisans' ways of mending sick hearts was it possible for me to understand not only how they reason and feel about the life-threatening serious illness, medical technology, and human body, but also how and why they do so. There are elements of Heartisan logic that are perhaps more clearly manifested in the ways in which their practice is structured and performed rather than in their more or less reflected-upon statements and stories. Because of my belief that Heartisans' knowledge and their shared system of meaning don't precede their practices, but are inherent to them, these were the elements that I found particularly interesting. The routinized ways in which doctors, nurses, assistant nurses, and patients i) move, handle, and talk about their own bodies, ii) approach, handle, and talk about bodies other than their own (as, for instance, those of Heartisan-patients), and iii) approach, handle, and talk about the objects (such as technological devices) make up a kind of cultural phenomena that reflect some of their deepest rooted understandings and attitudes.

However, I also believed that to limit the range of data to that generated through participant observation alone would seriously decontextualize the findings. Any kind of interpretation of such data would provide a far too distorted picture of Heartisans and Heartlands. In light of this, I do not agree with the Gusterson's emphasis on what he calls "polymorphous engagement" as a modern – more flexible and adjustable – alternative to the traditional method of participant observation (1997)¹⁷⁹. Instead, provided the unique power of participant observation, I see the polymorphous engagement as a way of fine-tuning the participant observation in harmony with the particular composition of given field of study by using, in a *bricolage* style, a wider collection of suitable ethnographic tools.

¹⁷⁹ See 'Beeing there... and there' section in CHAPTER TWO – METHOD above (pp 89)

Although this suggestion might appear superfluous, these methodological strategies fall, more often than not, outside of methodological discussions in ethnographic accounts. Perhaps it is because of the fact that these strategies nowadays seem obvious that anthropologists increasingly take them for granted and avoid discussing them. At the same time, by avoiding statement and explication of the obvious, the anthropological knowledge is rendered one-dimensional rather than 'thick' and deeply contextualized. This also means that the fine-grained reflections on methodological tools are no longer properly rehearsed in anthropological ethnographic accounts. Therefore, how can the various ethnographic strategies of dealing with translocal fields of human existence ever be discussed and improved if they are absent from ethnographies? I believe that acknowledging this as merely a matter of general knowledge, a secondary research, or a researcher's duty to be well informed about his research subject is to deny it its real value. Ultimately, an account of anthropological ways of dealing with translocality also accounts for what kind of translocality is in focus, which should be acknowledged as a valuable resource for future anthropological studies on the subject. One of the perhaps most obvious benefits of such accounts would lie in that it allows for various translocal fields of anthropological enquiry as well as for various compositions of ethnographic tools deployed in these different fields, to be more easily compared. Such comparisons would, in turn, show the patterned glimpses of nuances of what kind of circumstances different translocal phenomena are linked to, in what ways their contexts differ, or if they maybe are similar. Ultimately, they would enable further exploration of what kind of political, social, economic, and/or emotional forces lie behind these phenomena. The times when cultures were exclusively defined by the borders of the hamlet, village, city, region, or the nation state are long gone. Today cultures are increasingly being assembled around various translocal cultural phenomena. Hence, in the search for cultural universals and particulars, anthropologists might want to understand their

translocalities a bit better. Providing thorough accounts of what particular combination of ethnographic techniques the different translocal fields required, while at the same time remaining loyal to the unique powers of participant observation, might be one of the ways to achieve that.

Emotional notes

The strong emotional response that I have felt towards my field work directed my attention closer to the emotional dimensions of mechanical help-heart implantation treatment. By paying attention to my own emotional responses to the people, things, and/or events in the field I allowed my understanding of the ways in which Heartisans view human body, life, death, and medical technology to be less technical and more human. Drawing from this experience, I argue that the concept of ‘emotional notes’ is a valuable asset for anthropological work, especially in trying to understand those sides of human life that border on issues of end-stage illness, death, and suffering. What’s more, in the case of mechanical help-heart implantation treatment, the weight of the situation for each patient is in its very core emotional, in that they are facing the probability of losing their lives and their loved ones, enduring physical and emotional pain by submitting to the extremely violent treatments, and coping with inescapable death-defying uncertainty. Paradoxically, one of the main properties of mechanical help-heart implantation treatment is that the emotions are bracketed in order for the treatment to be doable at all. To get to the bottom of such things an anthropologist cannot afford to enter his/her field of study unemotionally.

Of course, a researcher’s emotional response tells us something about the researcher him or herself – an observation often used as a critique of the role that emotions might have in science. Still, in each of researcher’s emotional responses to his/her encounters with emotional dimensions of human life lies an important story about human ways that just can’t wait to be told. In anthropology,

emotional notes should be granted the status of a forest amidst the trees.

PRACTICAL/CLINICAL IMPLICATIONS

The aim of this research was to provide an analysis of a sophisticated and highly intricate nature of a mechanical help-heart treatment from an alternative angle, one that is accepting of the cultural and emotional sides of human life on the far side of despair. I aimed at discerning what kind of challenges emerge with these practices. Ethnographic evidence presented here shows that these astonishing technologies and practices through which lives are saved and sufferings of many are made easier, are always tied to uncertainty, bringing a variety of new challenges which more often than not are rather hard to forecast beforehand. Due to the ever-increasing focus on specialization, biomedicine has come a long way in exploring physiological bodies. In the meantime, as a science and ideology, it seems to have lost sight of those aspects of being human that can't fit within the tight frames of various medical specializations.

Clinical practices that make up the mechanical help-heart treatment are supported by medical scientific knowledge and are thus acknowledged as evidence-based. The human body is treated as a physiological compound of cells, tissues, organs, and substances. As this thesis shows, the heart patients are first examined (anamnesis and physical and technological examinations) whereby a disease, conceptualized as the unwanted presence of a deviating physiological condition, is identified (diagnosis). Thereafter, a suitable action is chosen to eliminate or reduce the effect of a disease (cure). Modern clinical practices are generally understood as dealing with curing rather than healing. This focus on curing (or lack of focus on healing) has been criticized as insufficient and more holistic approach to health and illness is advocated for (Strathern and Stewart 1999). Although this argument seems sound it gives a somewhat simplistic picture. In everyday medical practice these two concepts are quite easy to confuse. This is mostly due to the fact that biomedical training

does not provide enough room for knowledge that is not positivistic (physiological, biological, statistical etc.). This is one of the side effects of the cult of ‘evidence-based medicine’. The example of such error in biomedical curing that is shown in the following account of the Parkinson’s patients’ experience of Deep Brain Stimulation (DBS) fits nicely with, and thus confirms, the conclusions that I have made throughout this book:

... in some PD [Parkinson’s Disease] patients, their experience of this improvement and of the advantages of stimulation does not match the results, and their behavior is sometimes unsettling for the CRC team... patients were not satisfied or did not experience any social readjustment: some of them gave up their work even though they had fought to preserve it during their worst motor states; others complained that the stimulation did not work, or that they did not feel the benefit of it. Sometimes it was the family who complained that they did not recognize the patient or could not cope with his new way of life. In some cases, the conflict led to a divorce, or the patient came to hope for a return to the former condition and life. But in fact, none of them wished to stop the stimulation... The dimensions involved here are not pathological, but what the team identifies as issues of social adjustment. Although their motor disability is attenuated, the patients are not “socially adjusted”, as a neurologist explained, and have “trouble fitting into their family and professional environment”(Moutaud 2011: 250).

The observations I have presented in this book point in the same direction as this example. Strathern and Stewart (Strathern and Stewart 1999) point out that physicians are increasingly becoming aware of that there is more to treating a person than merely physiological curing. In addition to the specific physiological conditions that a person may have, the whole person needs to be taken care of. Yet, the fact remains that, while the concept of curing resonates better with the biomedical claim to scientific knowledge and the certainty of traceable evidence, the concept of healing seems to be

made marginal as a property of tradition and belief in the scientifically unexplainable. In the case of mechanical help-heart treatment, although the illness that is being treated is by definition incurable, the treatment focuses on the physiological and the biological. Still, whatever picture any given prognosis of this treatment might provide, the evidence it rests on is always ambiguous and permeated by uncertainty, and thus provides no warrant of success. This implies that clinical decisions about the treatment are based partly on scientific evidence, such as the results from randomized clinical trials, but also partly on the professional judgment based on the experience of a medical team and/or individual team members. Perhaps the most interesting thing here is that these judgments are as much based on faith invested in the efficiency and error-free workings of technology and medical craftsmanship as they are on scientific evidence. Medical science, its evidence-based practice, and the empirical traceability of the efficiency of this practice are major features of modern biomedicine that make it distinguishable from other traditional healing practices. In practice, however, this way of understanding the human body, health, illness, curing, and care-giving was manifested in Heartlands in that Heartisan-patients were commonly praised for enduring, for not complaining, and for behaving in a compliant manner. Any signs of grief, distress, and emotional burden were always explained as a temporary decline of an otherwise strong spirit, a brief moment of weakness, or as a pharmacologically treatable pathological condition such as depression. All in all, the emotionality of a treated person was often isolated as a disturbance.

Perhaps the more of the future that the medical professionals conquer, the deeper into the human body they intrude – which should be reason enough for the social, cultural, and emotional aspects of end-stage heart failure and its treatment to be seriously taken into account and even honored with a more central role during the whole treatment. Such a strategy would provide caregivers with the opportunity to optimize the sick persons' chances for smoother reintegration into their ordinary lives. Ethnographic evidence

presented in this book suggests that modern medical treatments and care-giving can be improved by allowing for these dimensions of being human to take a more central role in medical practice. This way, the patients would at least have a chance at being somewhat better prepared to cope with such radical changes which affect their very mode of existence. In other words, with improved and sustained focus on these qualitative dimensions of being human, medical professionals are more likely to adjust their treatments to the basic needs of human beings as feeling, social, and cultural species rather than the other way around.

Hospital Health Agents

In practice, perhaps this implies that the range of specializations in hospitals needs to be broadened to include some sort of *health agents* who should be educated and experienced in attending to the non-physiological sides of treated persons. For the time being, this role is played by counseling hospital social workers and hospital pastors. Nevertheless, the skills of the counselors are utilized from the outskirts of the epicenter of happenings. They often attend discussion meetings and, at some point during the treatment, they might approach the patient and sometimes also the patient's relative(s) to present themselves and offer them their counseling. The structural grid of their position – the fact that a counselor usually works at several clinics at once, or that he or she is not an ordinary part of the mechanical help-heart team meeting a patient on a daily basis throughout the entire treatment, but are more of a resource that may or may not be utilized – makes their role, and therefore also their perspective, somehow less significant than that of the doctors, nurses, and the more tangible physiological subject matters. Regarding the few hospital pastors, they are expected to be a resource for all the patients in the entire hospital – which means that their time is very limited and distributed across a large number of people. Furthermore, the role of hospital pastors is highly ambiguous due to several factors. For instance, their services are not often required by Heartisans.

Structurally, hospital pastors are even more marginalized than the counselors. In fact, in Heartlands there are no guidelines to rely on whenever a patient expresses his or her concern, worry, anxiety and/or fear of death (expressed in a way that is regarded as beyond normal)¹⁸⁰. Heart doctors would usually not know how to handle this situation. Most often, they'd ignore it for as long as possible. If the patient's complaints and concerns persist, a doctor would generally send for a psychiatrist colleague for consultation, hoping that the answer is strictly pharmacological. Nevertheless, neither the counselor nor the pastor is a given first-hand choice here. What's more, pastors are more often than not associated with things opposite to evidence-based science (such as religion, belief, holiness, and spirituality). Some of the pastors confided in me, telling me that they would like to change people's preconceived ideas about them. Patients seeing them as they walk down the hall, they say, would get frightened, probably thinking 'oh, no, it's time for me to die!', as if a pastor only comes to perform the last rites. Obviously, they want to be there for the terminally ill, but they believe to have much more to offer in the way of humane warmth, comfort, understanding, and spiritual guidance for all patients. Clearly, they think that it is a shame that they should always be associated with death. On the other hand, many patients are not religious at all. Those who are, might not feel at home in this particular religious context. These are some of the factors that make hospitals pastors' efforts to make a difference rather difficult.

As the ethnographic evidence shows, ritualized practices are fairly powerful. Perhaps this potency can be utilized to make some changes to improve health care. Practically, this means adjusting the form of the rituals in harmony with our social, cultural, and emotional selves and not the other way around. For instance, both counselors and hospital pastors can be given a significantly more central role in mechanical help-heart treatment. Nevertheless, in addition to this,

¹⁸⁰ See the episode with Doctor Jessica where she complains about the lack of rules and guidelines in heartlands for managing the patients who are sad, worried, or anxious (pp 303).

maybe the present circumstances call for a completely new hospital profession to be integrated into clinical work with patients hovering between life and death. A medical anthropologist could, no doubt, contribute to the treatment. First, by being devoted to the non-physiological aspects of each patient, such as their emotions, cultural background, and social relations, during the entire course of their tough and highly volatile treatment, perhaps medical anthropologists could find ways to steer away from overly painful collisions with the worlds of biomedicine and biotechnology. They could also help them deal with the world outside the treatment, at the point of the patients' reintegration into the ordinary course of life. Moreover, this perspective would probably also provide insights into some of the most essential practicalities of life with a mechanical help-heart, which might be very useful in improvement and further development of this particular technology. Hopefully, alongside the hard clinical facts about the ways in which blood cells react to the violent rotations of a pump's impeller (or other similar physiological/technical kind of information), the facts about the patient's own experience of the usability of their holsters, the weight of extra batteries and back packs, lightning conductors, and various possible emergencies such as late trains and empty tanks, would gain in importance in the near future. This way, both the device manufacturers and also the authorities¹⁸¹ could benefit from collaborations with these health agents in addition to the already established collaboration with medical doctors.

SOCIAL SIGNIFICANCE

By providing an alternative take on the Heartisans' use of modern medical technology to manage serious chronic illness, this study deepens our understanding of the relationship between human beings and medical technology in general. Justified by the scientific expertise, this biotechnological domain is built upon particular understanding of the actual lived human body – the body that is also defined through ritualized practices of managing heart failure. In these practices the

¹⁸¹ Such as the Swedish Social Insurance Agency.

abstract biomedical concepts and understandings are confirmed and installed in "... wider institutionalization of medicine within the state", on a biopolitical level (Brown and Webster 2004). Thus, the social significance of the insights that are presented in this thesis must not be overlooked.

On a theoretical level, this study portrays the impact that the humanity's apparent belief in progress and technology has on the ways in which people view themselves and also on their general being in the world. Taking this into account, we can better see how these insights can be implemented into the clinical practice and for what purposes, namely that a more culturally and socially oriented auditing and navigating of our high-tech medical interventions should be applied, primarily for the benefit of individual patients, and therefore also for the benefit of the society as a whole. Furthermore, the wide-ranging contextualization of these practices, as they are situated in the large-scale transnational context with multiple forces and actors at work, provides a sense of the particular character of their political and economic currents that should not be neglected. A dynamo of the particular kind of hope that is created through these local clinical practices is generated through a large-scale nexus of economic and political forces of which these local clinical practices are part. The progress of medical science and technology has provided medical professionals with tools with which they believe they are able to predict the future for the examined patient. Hence they form a techno-scientific keystone for their envisioning of the future through the practices of clinical prognosis (foundation of hope). In the meantime, under the normative weight of dominant biomedical discourse patients are made responsible for managing their present in the light of this new knowledge about their future, and also of not giving up in face of adversity. Such responsibilities are tied to the particular sense of morality (the virtue of hope) as the advantages brought by the technological development are treated as something that ought to be exploited. This, in turn, stimulates the patients' and medical professionals' hope for innovations that hold the power to

treat or cure, which is a very foundation of the promises made by the Medical Industrial Complex (the industry of hope). Moreover, it stimulates the circuits of investment (the finances of hope) and reinforces the creation of biotech norms and values (the cultures of hope). Ultimately, through enactment of hope rites people are literally saved from dying. In the surrounding biomedical discourse and throughout the news bulletin and popular culture, such survivors are readily presented as success-stories and symbols of biotechnological triumph (the proof of hope).

How much unregulated power should the private vendors – in the name of progress – be entrusted with? How much can they handle? What actions need to be taken so that the business of profit-making doesn't infringe on the primary aims of medicine (saving lives and alleviating pain), or on patients' emotional, social, and cultural selves? Ultimately, how can it be avoided that the influence that this global *bioeconomy* (advertisement, market-economy and financial investments and turnovers of MIC) has on how people around the world view human body, health, life, death, and well-being, gets far too strong? What kind of influence would, in this context, count as far too strong?

This study shows that in these elements of mechanical help-heart treatment (and any other high-tech clinical practice dealing with severely sick people) it is important that they are not neglected if their potent propensity to reduce human life to measurable and observable flows of physiological processes on the one hand, and of financial investments and turnovers on the other, is to be avoided. By raising these often rather unsettling questions of meaning and morality inherent to these circumstances, at least we have a chance of taking action to negotiate the terms under which we conduct our practices of care so that they allow us to see and attend to more than just our body mechanics.

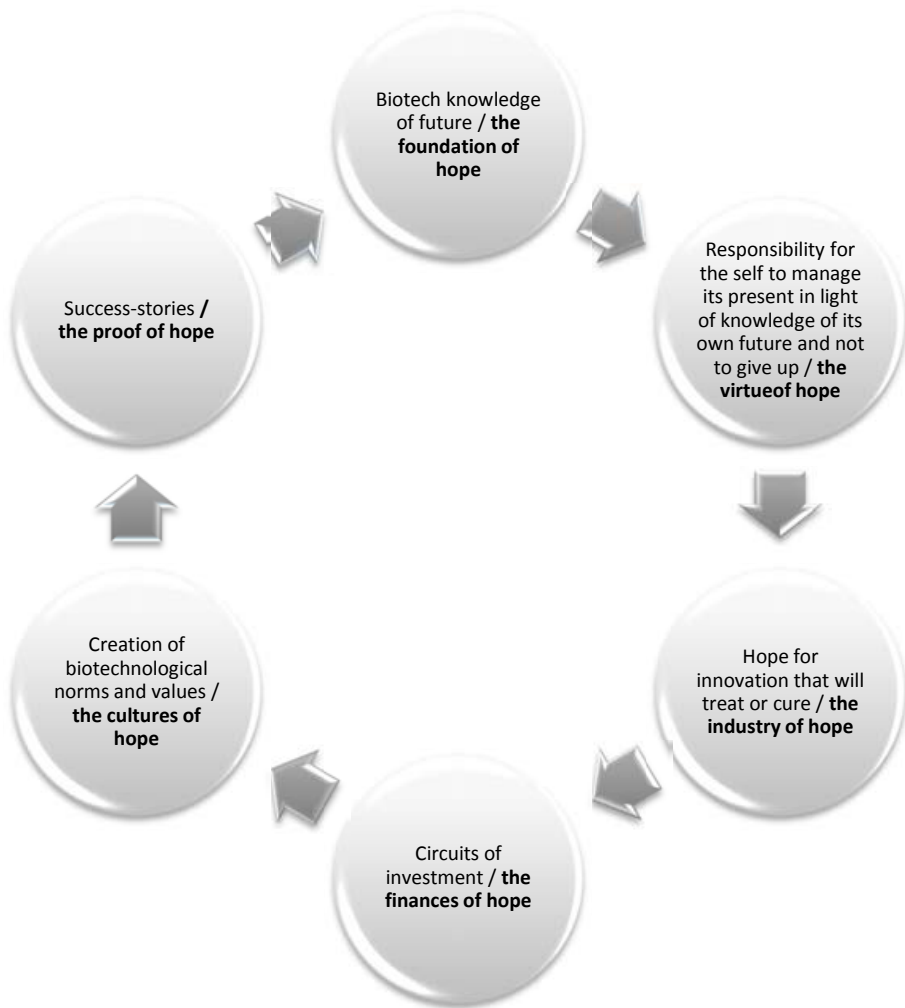


Figure 41: Dynamo of hope

SOME POINTERS FOR FURTHER STUDIES

On the whole, future anthropological studies of life with transplanted hearts, ventricular assist devices, and total artificial hearts should be conducted both inside and outside the hospitals, amongst the medical professionals, patients, their relatives and/or various patient support groups in a variety of cultural contexts. This way a more wide-ranging and hopefully also a bit thicker understanding of their ways of living

and also of their ways of relating to themselves, each other, and other people could be gained. Studying these phenomena in different contexts would enable comparison between various characteristics of ways of coping with serious illnesses with the help of modern technology.

For more detailed understanding of what it is like to live with a mechanical help-heart (or with a Total Artificial Heart) an ethnographic study of patients' lives at home after discharge from the hospital would be desirable. By spending time with patients on a daily basis, closely following their daily routines, and mapping their kin- and social networks while talking with them about how they view their situation, their bodies, the medical treatment, and their ambitions in life, a researcher could understand the deep impact that this illness and this treatment have on these people. Such an understanding could be very valuable in two aspects. First, it would provide further pointers about where the relationship between medical technological innovations, society, and the human body is heading. Second, such a close-up portrait of what it means to be a human living with a mechanical heart would also be of practical value for clinicians who perform these treatments and ultimately also for the further development and/or improvement of this kind of medical technology.

Translocality is yet another interesting dimension of this particular technology. Therefore, a study focusing on a mechanical help-heart, from clinical trials, design development, lab experiments, and testing facilities through advertisement and distribution to actual implantation would be of particular significance for ethnographic attempts to appreciate the kind of dynamics and impact that these devices gain throughout the course of their life cycles. In other words, their social and cultural life, as they transform from an idea to a fully functioning and implanted help-heart, would be the very target of anthropological attention. This perspective would provide insights into the cultural dimensions of artifacts which thus far mainly have been considered from engineering and physiological/biological points

of view. Medical science and technology are constantly developing and have been very helpful to humanity during the past century or two, both in terms of the general knowledge about various aspects of human life and also in terms of various ways in which technical solutions make our lives easier and more colorful. Nevertheless, regarding any deeper understanding of how people actually manage living in the dust of biomedical progress, we still have a lot to learn.

Fresh innovations and newly conquered frontiers provide new outlooks. As a result, they show things in a new light. Therefore, advanced surgery in general is interesting as a particular class of ritualized practices where the medical fields of victory (human bodies) are equated with mankind's conquering of the future. The ways in which people upgrade their bodies so as to resemble their dreams of what their bodies should be like express their particular views on the authenticity of the body as it is being negotiated on the borderline between nature and culture. Exploring and analyzing this particular kind of practice enables an understanding of the kind of power that the development of medical knowledge and technology has on how people sense the world. Consequently, it helps us appreciate the impact that medical knowledge and technology has on how people live their lives.

After all, new cultural forms are not limited to the confines of biomedicine. They can be observed in any domain of human life where innovations are being implemented and where dreamed-of potentialities are being actualized. This includes anything from daring architectural projects, infrastructural advances, and new paths of information and communications technology to revolutionizing robotics, artificial intelligence, and bold space programs.

This study shows that, in the case of mechanical help-heart treatment, the mid-leaps from now to tomorrow are enabled by the sense of hope. The formalized practices through which the future is brought into being and through which people embody new cultural forms are structured and designed so as to instill a sense of hope. What's more, through the ways in which these practices are

performed, hope is rendered a virtue. Thus, the hope that is manifested through the medical expertise and new technology is treated not as an option but as a moral code, i.e. a rule expressing “a social ‘ought’” (Reckwitz 2002). It is stretched beyond the individual sense of future-oriented anticipation and made into a social duty. As such, it is also made into an important pillar of the large-scale-project-progress. This particular feature of new cultural forms, where people’s emotional ways of sensing the world are being reduced to rigid templates of institutionalized practices in the service of a societal urge for progress, is perhaps an important element of what it means to be human, and should therefore have a place as the key subject of contemporary anthropological analysis.

EPILOGUE

COLLECTIVE LIMINALITY

Modern biomedical treatments bear a strong resemblance to traditional healing rituals in aspects like their structure, aims, scenarios, performance, roles, and referential frames. In addition to the evidence-based approach of biomedicine, together with the empirical traceability of its workings, perhaps the most apparent difference between modern and traditional treatments lies in the fact that the modern ones use more sophisticated technology and have their attention directed towards the future (hope and progress) rather than to the past (tradition and ancestors). Another readily noticeable difference is that modern treatments are inherently translocal and are to a greater extent also tied to large networks of processes on a global level. Hence, while each mechanical help-heart treatment is an individual history about suffering, uncertainty, and hope, it is also a social history about the biomedical quest towards the future.

One of the most powerful aspects of these characteristics of modern biomedical treatments is the status they enjoy on almost all societal levels, from journalism and advertisement to various forms of popular culture such as sci-fi movies or trendy programs depicting hospital life (documentary, semi-documentary, and fictional). The relationship between popular culture and medicine and technology is far from uncomplicated; developments in medicine and medical technology are always preceded by their own forecast in sci-fi literature and films or in other genres of popular culture (Squier 2004). The idealization of miraculous possibilities of medicine and technology in popular culture serves as a kind of ideological immunosuppressant, making sure that future medical practices and technologies do not get rejected upon their arrival (Squier 2004: 200).

In the meantime, each local clinical performance of a mechanical help-heart implantation makes a significant element of the propelling forces in the large-scale biomedical and biotechnical march towards the future. It is in and through the hope rites that biotechnological

imaginaries are being realized, the possibilities actualized. In short, they make medical dreams come true. They also generate arresting headlines circling across the public space. The success of each treatment legitimizes the supremacy of progress and the power that awaits its revelation in the eternally proximate corner of the future. At the same time, each medical breakthrough and each technological innovation opens up a whole new set of as yet unanticipated fields of practices and brings new challenges that need to be managed. This results in a peculiar succession of events leading towards the imagined miracle of potent medical and technological progress shining from ahead – the very generator of hope. One such succession, or chain of events, can be seen in the development of antiseptics which has made open-heart surgery possible which, in turn, has resulted in more lives saved from clogged heart vessels and heart attacks which, again in turn, gave rise to ever-increasing incidence of heart failure. Another one taking place simultaneously is the development of immunosuppressive drugs, enabling organ transplantation practices which, in turn, resulted in a new phenomenon of a “shortage” of donor organs which, in turn, called for development of technological substitutes for these organs so that the supply can meet the demand (Figure 42).

This movement is composed of a number of processes taking place simultaneously. The best way to illustrate this would perhaps be to render it as a diachronic graft, a two-way catheter through time, or a tunnel through which:

1. The ever-insufficient human body is enabled to bypass the risks and shortcomings of the present and to access the opportunities of the future.
2. The continuous inflow of the future, dressed as a new, fresh, dose of ideological immunosuppressant, is enabled from the creative realm of science and fiction and medical imaginary (property of future) into the realm of the ever-insufficient human body (property of present).

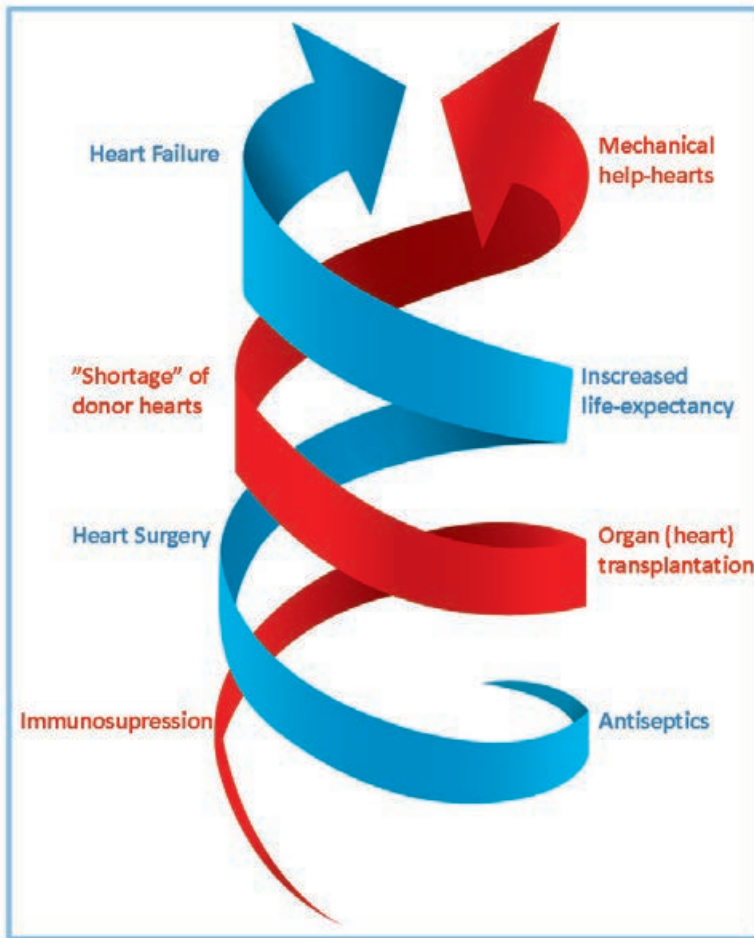


Figure 42: A tunnel of progress made up of multiple simultaneous successions of events (technological innovations, medical breakthroughs, and cultural changes)

Thus, a mechanical help-heart implantation treatment is one of many propelling operative forces in this liminal tunnel (progress) through which the deteriorating present (life crisis) is ritually bypassed and future potentialities (hope) ritually actualized. Success-stories are carved into the bodies of surviving patients as a ceremonial witness of the victory of technoscience. As a result: the science fiction ideological immunosuppressant gets an extra boost and becomes even

more effective. As mechanical help-hearts are implanted, the human body is transformed into a never-ending technoscientific body project through which the future is brought into being. The ambiguity of this particular kind of new postmodern liminality lies in the question of whether the mechanical help-heart implantation treatments are merely appropriating the potentialities of future or if they are performative projections of a technoscientific future? Are we shaping the future to suit us or are we shaping ourselves to suit our vision of the future?

When it comes to the human heart, the mechanical help-heart implantation practices studied here show that its current shape and significance belongs to the future. Medical imaginaries, inspired by that-which-is-not-yet futuristic visions in popular culture and science fiction, provide real tangible design sketches which eventually lead to the construction of first prototypes. Standardized clinical practices, where these new treatments are put into practice, bring this future into being by shaping the body of the chronically sick according to the visions of future. In contrast to the Trobriand Islanders' and Australian aborigines' worship of their past, postmodern clinicians focus on the miraculous powers of the future by ritually bringing them into being.

Just as the patients find themselves in a new mode of liminal existence between death and life and health and illness, the whole biomedical and biotechnical movement seems to be caught, indeterminately, between the discomfort of the dirty and finite present and the potentiality of a shiny and promising future. Here, through the web of mutually implying technoscientific practices and the kind of culture they help create, the liminality surfaces as a collective rather than as a personal way of being in the world. The fact that popular culture propels the technoscientific commitment while at the same time providing excitement and hope to people and stimulating the circuits of financial investment in biotechnical research and development shows the highly explosive, potent, and unpredictable character of the collective movement created through these practices. The aim seems to be the colonization of the future.

Nevertheless, as the future is open-ended, so is also the proximity of its grace. Hence, liminality increasingly becomes a permanent order of things. The temporary and explicitly extraordinary anti-structure of liminality turns more and more into an ordinary and 'natural' way of being. This liminality cannot just be explained as a manifestation of temporary experienced parallax – as when things are not what they appear to be due to the change of perspective. It comes alive and thrives in the space in-between, breaking out of conceptual boundaries, such as human/machine and health/illness. By doing so, it challenges the formal logic by bringing the contradiction in as its most significant element. What once was in between is becoming all-encompassing. The technological visions of future appear as the acoustics and mirror of modern worldviews. In this liminality, the truth no longer belongs to everybody – the dream of humanist naïveté gets all torn here. Instead, the truth is forged in the space between the three great M's: Mankind, Machine and Medicine.

Densely intertwined undercurrents of cultural values such as future-oriented concepts of progress, achievement, and success – for all of which the norm of a functional body is imperative and beyond doubt – continuously update Heartisans' ways of knowing and feeling the world. The mechanical help-heart treatment is part of a continuous process of self-reflexive individual participation in formalized collective practices where the understandings of life-threatening chronic illness, body, and medical knowledge and technology are shaped, re-shaped and developed in a narrative of progress. In this process, the course of embodiment of cultural influence and institutional pressure is being upgraded and (consciously or not) made more progressive – namely it brings technology that in turn, when deployed, further enhances and amplifies the very same modes of embodiment that brought those technologies to life in the first place. Not only are the bodies being upgraded in accordance with what we expect from the future, but our societal progressing is being upgraded through actualization of a potentiality that in turn opens up a whole new field of new

potentialities to be worshipped and pursued. Bioengineers who work with developing mechanical help-hearts view the human body as something that not only needs maintenance, but that also needs to be perfected (Sharp 2011). Heartisans, on the other hand, are actively running down a dream of progress by performing the rites of hope in the face of a serious life crisis. In the meanwhile, the patients' social, cultural and emotional selves remain significantly unattended, as if these aspects of being human are but weaknesses, i.e. the imperfections that are just in the way of the mankind's march towards the promises of future. Those times when hope rites are regarded as successful and the patients manage to get through, away from the threat of life crisis and into the promise of a desired future, their social, cultural, and emotional selves seem to have spent too much time in isolation. Thus, they appear unprepared for the life in this future that has now been brought into being. So these patients end up in an extended present, unable to either bring back the long-gone days and nights from their past nor to keep up the pace with a future-hungry society.

HOPEHUNTERS

It seems inherent to the nature of technological development that new medical treatments and technologies tend to become old and are, sooner or later, substituted by other new ones. In the meantime, stories about survivors offer inspiration and the will to fight – encouragement not to give up when times are tough and when there seems to be no way out. These success-stories are nevertheless typical of contemporary Western culture, or more exactly constitute a fundamental part of the American Dream. The opportunities of greater material prosperity, education, and career are there to be achieved. These stories offer inspiration, hope, and promises while opening wide the doors of opportunity. Poor kids from the projects, immigrants, the ill and disabled, and underdogs of all kinds are portrayed as victorious due to their persistence. If you are goal-oriented and have resolute determination, you can make it as a

successful musician, beloved actor, top lawyer, company executive, board member, or whatever – all thanks to the combination of the opportunities available and your own efforts to achieve them. The key word is achievement, which implies personal effort to progress and strive forward. In fact, any sign of an attempt to question the idea of progress, or the price of the gain, would most certainly mark the dissenter as conservative and backward-looking.

The echo of the “If I can do it, so can you!” message is now surfing the big waves of success-stories that are flooding the world with motivation and vigor. What’s more, there are several synchronic currents of progress at work, each giving and receiving the impetus to and from the other ones in a diachronic picture of global, let’s call it, metaprogress. These include personal progress, collective or group progress, societal progress, economic progress, scientific progress, and technological progress. The idea of progress is continuously being armored and invigorated by and through the joint action taking place among these currents. This wide-ranging belief in progress has been fueling the Western parade towards the future since the dawn of the Enlightenment (Ferrarotti 1985; Frängsmyr 1990). Progress was, and still is, regarded as limitless, perpetual, natural, and indispensable (von Wright 1993). Personal progress contributes to collective, societal, economic, scientific, and technological progress, which in turn are opening up the new worlds of amazing possibilities for further personal progress, and so on.

The problem of iconic portrayals of success-stories is that they rest on and uphold socio-culturally constructed ideals of achievement. Based on societal expectations of progress as goal-oriented self-improvement and self-development, they leave a great deal of responsibility for the outcome of their situation squarely up to the individual. Accordingly, the same message is reaching the chronically ill, whose conditions are depicted as the result of their own will, or lack of it, to stay away from the risk factors and to fight the illness. What’s more, the question of whether these success-stories, while essential as energy-boosters of optimism, are representative of all

people in similar situations, is easily eclipsed by their sheer power. Can we be so spellbound with the portrayed heroes?

One of the most obvious things this study shows is that the relationship between humans and modern technology is for the most part rather paradoxical as it is both awe-inspiring and binding. People are devoted to their machines and to the principle of progress inherent to them. Yet everything takes place as if this relationship is built on the state of dependence. As a result, it is endowed by contractual moral obligation. In the light of ever-rising biomedical and biotechnological authority, alongside mankind's ever-increasing dependence on its powers, the fact that the routine question "How do I feel?" has at least two different but equally important meanings seems more crucial than ever before.

The concept of progress, with a more or less undisputed hegemonic status in modern world, appears as a paradox where tomorrow's history is yesterday's news, rendering each innovation but a stepping stone to the next one. The goal, it is clear, is a thought still unknown, although it readily seems to be presented as something known yet unthought, as bioengineers, medical scientists, and clinicians appear certain that the goal is knowledge that is always somewhere out there, up ahead. All that needs to be done is for it to be thought of. Nevertheless, knowing the goal entirely would also mean acknowledging the end of this collective striving for renewal, improvement, and perfection. This seems unthinkable. Hence, the goal of the progress (the noun) is not to actually progress (the verb) to a new, better, stage. The goal of achievement is not to achieve. In this context, destinations signify the dreadful finitude. The goal is to keep progressing and to keep achieving, to proceed and to perpetuate the cycle of progress for the sake of progressing. In the meantime, the pace, scope, and depth of the progress are determined by the current state of medical imaginary. Should they lag behind, all aspects of being human – biological as well as social, cultural, and emotional – are either upgraded in accordance with this imaginary or, when this is not possible, denied significance. Hope lays hidden in this

perpetuality, not in the arrival. The dread of arrival lies in that it threatens to put an end to continuity. Then we'd have nothing to hope for. The chase seems, after all, to be better than the catch. Perhaps we have always been hunters and gatherers. This time, instead of wild game, we hunt for the promises of hope. Instead of hiding in dense bushes or deep holes and caves, they hide in the haze of the future. Instead of using spears and axes, we colonize the new unknown grounds of the future and conquer our new prey with the power of new ideas and technological innovations. Each time we succeed, the conquered promise (the realization of what we hoped for, the actualized potentiality) turns, like a snowflake in the palm of a hand, into something else. Hence, we pick up our hunting gear and run on to the next one. We call it progress. In the end, what would the world we know be like if the progress were just to stop?

The ways in which illness, body, and remedy are conceptualized in practices of a mechanical help-heart implantation, are in many ways different from those of premodern societies so often portrayed in classical works of anthropology. By seeking guidance in their past (tradition and ancestors) or in the atemporal mystical powers of spells and rituals in order to manage their present, Trobrianders, aborigines, Ndembu, or Azande seem to retain a rather wide-ranging vision, a broad and inclusive take on the world, unrestricted by any specific 'direction'. Hence, they also appear more susceptible and responsive to their immediate surroundings, to themselves and each other, as well as to their deities and ancestors, in a way decreasingly familiar to the perspectives of the Western world. On the other hand, considering the nature of medical imaginaries, science fiction movies, or of cover stories, arts and literature on medicine and technology, and of clinical experiments and practices (let alone private and governmental cultural and emotional as well as financial investments),

the Western world is clearly more and more focused on the future, expecting that it might shed some light on peoples' ever-so-dark present. Instead of striving to be wide-ranging, our vision seems by its rigid directedness to be increasingly narrowed down to a tunnel vision. And how do we know for sure that the light at the end of our tunnel is not just another train?

Bibliography

- Adams, A., and T. Schlich
2006 Design for control: surgery, science, and space at the Royal Victoria Hospital, Montreal, 1893-1956. *Med Hist* 50(3):303-24.
- Agar, Michael
1996 *The Professional Stranger: an Informal Introduction to Ethnography*. San Diego: Academic Press.
- Alberti, Fay Bound
2007 The Emotional Heart. *In The Heart*. J. Peto, ed. Pp. 125-142. New Haven and London: Yale.
- Allan, Helen
2007 Experiences of infertility: liminality and the role of the fertility clinic. *Nursing Inquiry* 14(2):132-139.
- Andaya, Elise
2009 The Gift of Health. *Medical Anthropology Quarterly* 23(4):357-374.
- Anderson, Jennifer L.
1987 Japanese Tea Ritual: Religion in Practice. *Man* 22(3):475-498.
- Atkinson, Paul
1995 *Medical talk and medical work : the liturgy of the clinic*. London: Sage.
- Bartlett Foote, Susan
1992 *Managing the Medical Arms Race: Innovation and Public Policy in the Medical Device Industry*. Berkeley: University of California Press.
- Beaglehole, R., and D. Yach
2003 Globalisation and the prevention and control of non-communicable disease: the neglected chronic diseases of adults. *The Lancet* 362(9387):903-908.
- Beauchamp, Tom L., and James F. Childress
2001 *Principles of biomedical ethics*. Oxford ; New York: Oxford University Press.
- Behar, Ruth
1996 *The vulnerable observer : anthropology that breaks your heart*. Boston: Beacon Press.

- Bell, Catherine
1987 Discourse and dichotomies: The structure of ritual theory. *Religion* 17(2):95-118.
- Bell, Catherine
2008 Embodiment. *In* *Theorizing Rituals: Issues, Topics, Approaches, Concepts*. J. Kreinath, J. Snoek, and M. Stausberg, eds. Leiden, Boston: Brill NV.
- Bell, Catherine M.
1992 *Ritual theory, ritual practice*. New York ; Oxford: Oxford University Press.
- 1997 *Ritual: perspectives and dimensions*. New York ; Oxford: Oxford University Press.
- Benedict, Ruth
1989[1934] *Patterns of culture*. Boston: Houghton Mifflin.
- Björklund, Ulf
2001 Att studera en diaspora: den armeniska försakingringen som fält. *In* *Flera fält i ett*. U. Hannerz, ed. Pp. 86-107. Stockholm: Carlssons.
- Bleumink, Gysèle S., et al.
2004 Quantifying the heart failure epidemic: prevalence, incidence rate, lifetime risk and prognosis of heart failure. *European Heart Journal* 25(18):1614-1619.
- Bosk, Charles L.
1980 Occupational Rituals in Patient Management. *New England Journal of Medicine* 303(2):71-76.
- Bourdieu, Pierre
1977 *Outline of a Theory of Practice*. Cambridge: Cambridge University Press.
- Braidotti, Rosi
2006 Posthuman, All Too Human: Towards a New Process Ontology. *Theory Culture Society* 23(7-8):197-208.
- Bringa, Tone
1995 *Being Muslim the Bosnian way : identity and community in a central Bosnian village*. Princeton, N.J.: Princeton University Press.
- Brody, Donald
1991[1990] *Sociologi och epistemologi - om Pierre Bourdieus författarskap och den historiska*

- epistemologin. Stockholm: HLS Förlag.
- Bronzino, Joseph D., ed.
1995 The biomedical engineering handbook. Boca Raton: CRC Press : IEEE Press.
- Brown, Nik, and Andrew Webster
2004 New Medical Technologies and Society. Cambridge: Polity Press Ltd. .
- Bruner, Jerome S.
2000[1990] Acts of meaning. Cambridge, Mass. ; London: Harvard University Press.
- Bukhman, Gene, and Alice Kidder
2008 Cardiovascular Disease and Global Health Equity: Lessons From Tuberculosis Control Then and Now. Am J Public Health 98(1):44-54.
- Butler, Judith
1990 Gender trouble : feminism and the subversion of identity. New York ; London: Routledge.
- Butler, Judith
2005 Könet Brinner! Texter i urval Natur och Kultur.
- Casper, Monica J., and Barbara A. Koenig
1996 Reconfiguring Nature and Culture: Intersections of Medical Anthropology and Technoscience Studies. Medical Anthropology Quarterly 10(4):523-536.
- Charmaz, Kathy
1983 Loss of self: a fundamental form of suffering in the chronically ill. Sociology of Health & Illness 5(2):168-195.
—
1991 Good days, bad days : the self in chronic illness and time. New Brunswick, N.J.: Rutgers University Press.
—
1999 *Stories of Suffering: Subjective Tales and Research Narratives*. Qualitative Health Research 9:362-382.
—
2006 The Power of Names. Journal of Contemporary Ethnography 35(4):396-399.
- Coffey, Amanda, Beverly Holbrook, and Paul Atkinson
1996 Qualitative data Analysis: Technologies and Representations. Sociological research Online 1(1).
- Colin Mathers, Ties Boerma, and Doris Ma Fat

- 2008 The global burden of disease: 2004 update. D.o.H.S.a. Informatics.
- Coulehan, Jack
2003 Metaphor and Medicine: Narrative in Clinical Practice. Yale Journal of Biology and Medicine 76:87-95.
- Crapanzano, Vincent
2003 Reflections on Hope as a Category of Social and Psychological Analysis. Cultural Anthropology 18(1):3-32.
- 2010 "At the Heart of the Discipline": Critical reflections on Fieldwork. *In* Emotions in the Field: The Psychology and Anthropology of Field Experience. J. Davies and D. Spencer, eds. Stanford, Calif.: Stanford University Press.
- Crowley-Matoka, M., and M. Lock
2006 Organ transplantation in a globalised world. Mortality 11(2):166-181.
- Dahlén, Tommy
1997 Among the interculturalists : an emergent profession and its packaging of knowledge. Stockholm: Stockholm Studies in Social Anthropology.
- Davies, James, and Dimitrina Spencer
2010 Emotions in the field : the psychology and anthropology of fieldwork experience. Pp. xi, 276 p. Stanford, Calif.: Stanford University Press.
- DelVecchio Good, Mary-Jo
2001 The Biotechnical Embrace. Culture, Medicine and Psychiatry 25(4):395-410.
- Denzin, Norman K.
1997 Interpretive ethnography : Ethnographic Practices for the 21st Century. Thousand Oaks, Calif. ; London: Sage.
- Desjarlais, Robert R.
1992 Body and emotion : the aesthetics of illness and healing in the Nepal Himalayas. Philadelphia: University of Pennsylvania Press.
- Devereux, George
1967a From anxiety to method in the behavioral sciences. The Hague,: Mouton & Co.
- 1967b From anxiety to method in the behavioral sciences. New York,: Humanities Press.

- Douglas, Mary
 2001 [1966] *Purity & Danger : An Analysis of the Concepts of Pollution & Taboo* Florence, KY, USA: Routledge [Taylor & Francis e-Library].
- 2010[1966] *Purity & Danger : An Analysis of the Concepts of Pollution & Taboo* London and New York: Routledge [Taylor & Francis e-Library].
- Downey, Gary Lee, Joseph Dumit, and Sarah Williams
 1995 *Cyborg Anthropology*. *Cultural Anthropology* 10(2):264-269.
- Durkheim, Émile
 1915 *The elementary forms of the religious life : a study in religious sociology*. London
 New York: George Allen & Unwin ;
 Macmillan.
- Ehn, Billy , and Orvar Löfgren
 2001 *Kulturanalyser*. Malmö: Gleerups Utbildning AB.
- Ehrenman, Gayle
 2003 *A whole new heart*. In *Mechanical Engineering Magazine*.
www.memagazine.com: The American Society of Mechanical Engineers.
- Encyclopaedia-Britannica
 2010a Merriam-Webster Online Dictionary, 11th edition.
- Encyclopaedia-Britannica, Online
 2010b "anamnesis".
- 2010c "myth".
- Estes, David N.
 2010 *Medical-Industrial Complex: Encyclopedia of Sociology*.
- Evans-Pritchard, E. E.
 1976[1937] *Witchcraft, oracles, and magic among the Azande*. Oxford: Clarendon Press.
- Ferrarotti, Franco
 1985 *The myth of inevitable progress*. Westport, Conn. ;
 London: Greenwood.
- Fischer, Michael M. J.
 1991 *Anthropology as Cultural Critique: Inserts for the 1990s Cultural Studies of Science, Visual-Virtual Realities, and Post-Trauma Politics*. *Cultural Anthropology* 6(4):525-537.

Foucault, Michel

1982 The Subject and Power. *Critical Inquiry* 8(4):777-795.

—

2003[1975] Övervakning och straff - Fängelsets födelse.
Lund: Arkiv Förlag.

—

2004[1976] Sexualitetens Historia - Viljan Att Veta. 3
vols. Volume Band 1. Uddevalla Media Print AB.

—

2006[1972] History of Madness. Oxon: Routledge.

Foucault, Michel

2006[1963] The Birth of the Clinic - An archaeology of
medical perception. London: Routledge Classics

Foucault, Michel, and Jay Miskowiec

1986 *Of Other Spaces*. *Diacritics* 16(1):22-27.

Fox, Renée C., and Judith P. Swazey

1974 The courage to fail: a social view of organ transplants and
dialysis. Chicago: University of Chicago Press.

—

1992 Spare parts : organ replacement in American Society. New
York: Oxford University Press.

Frazer, James George

1890 The golden bough : a study in comparative religion. 2 vols.
London: Macmillan.

—

1935[1910] Totemism and exogamy : a treatise on
certain early forms of superstition and society. London:
Macmillan.

Frängsmyr, Tore

1990 Framsteg eller förfall : framtidsbilder och utopier i
västerländsk tanketradition. Stockholm: Allmänna Förlaget.

G&C, Merriam Co

1913 Webster's Revised Unabridged, 1913.

Gane, Nicholas

2006 When We Have Never Been Human, What Is to Be Done?:
Interview with Donna Haraway. *Theory Culture Society* 23(7-
8):135-158.

Garfinkel, Harold

1967 Studies in ethnomethodology. Englewood Cliffs, N.J.,:
Prentice-Hall.

- Geertz, Clifford
 1995 *After the fact : two countries, four decades, one anthropologist*. Cambridge, Mass.: Harvard University Press.
- 2000[1973] *The Interpretation of Cultures*. New York: Basic Books.
- Gluckman, Max
 2006[1965] *Politics, law, and ritual in tribal society*. New Brunswick, NJ: Aldine Transaction.
- Goffman, Erving
 1961 *Asylums : essays on the social situation of mental patients and other inmates*. Garden City, N.Y: Anchor Books.
- 2003[1955] *On Face-Work: An Analysis of Ritual Elements in Social Interaction*. *Reflections* 4(3):7-13.
- 2005[1967] *Interaction Ritual : essays in face-to-face behavior*. New Brunswick, New Jersey: Transaction Publishers.
- Goody, Jack
 1961 *Religion and Ritual: The Definitional Problem*. *The British Journal of Sociology* 12(2):142-164.
- 1977 *Against "Ritual": Loosely Structured Thoughts on a Loosely Defined Topic*. *In Secular Ritual*. S.F. Moore and B.G. Myerhoff, eds. Assen: Van Gorcum.
- Gramsci, Antonio
 2007[1975] *Prison Notebooks*. J.A. Buttigieg, transl. Volume III. New York: Columbia University Press.
- Granfeldt, Hans
 2010 *The use of mechanical circulatory support and passive ventricular constraint in patients with acute and chronic heart failure* Medical Dissertation, Department of Medicine and Care, Linköping University.
- Grimes, Ronald L.
 1990 *Ritual criticism : case studies in its practice, essays on its theory*. Columbia, S.C: University of South Carolina Press.
- 2000 *Deeply into the bone re-inventing rites of passage*. Berkeley: University of California Press.
-

2008 Performance. *In* Theorizing Rituals: Issues, Topics, Approaches, Concepts. J. Kreinath, J. Snoek, and M. Stausberg, eds, Vol. 114-I. Bstn: Brill NV.

Guillemin, Marilys

2004 Embodying Heart Disease Through Drawings. *Health (London)* 8(2):223-239.

Gusterson, Hugh

1996 Nuclear rites: a weapons laboratory at the end of the Cold War. Berkeley ; London: University of California Press.

—

1997 Studying Up Revisited. *PoLAR Political and Legal Anthropology Review* 20(1):114-119.

Hadolt, Bernhard

1998 Locating difference: A medical anthropology 'at home'? *Anthropology & Medicine* 5(3):311-323.

Hannerz, Ulf

2000[1996] Transnational Connections: Culture, people, places. London and New York: Routledge.

—, ed.

2001 *Flera Fält i Ett: Socialantropologer om Translokala Konflikter*. Stockholm: Carlssons Bokförlag.

—

2003 Being there... and there... and there!: Reflections on Multi-Site Ethnography. *Ethnography* 4(2):201-216.

Haraway, Donna

1991 *Simians, Cyborgs and Women: The Reinvention of Nature* New York: Routledge.

—

1997 *Modest_Witness@Second_Millennium. FemaleMan@_Meets_OncoMouse™ : Feminism and Technoscience*. New York: Routledge.

Harper, Douglas

2008 *Onlyne Etymology Dictionary*.

Hastrup, Kirsten

1995 *A passage to anthropology : between experience and theory*. London: Routledge.

Heart Hope

2010 UT Southwestern Patient Among First in North Texas to Receive Permanent Heart Implant *In* Recent Stories, Vol. 2010: UT Southwestern Medical Center.

HeartHope

2011 Patient Testimonials *In* Patient Testimonials, Vol. 2011: UT Southwestern Medical Center.

Helman, Cecil G.

2001[1984] Culture, Health and Illness. London: Arnold.

Hertz, Rosanna, and Jonathan B. Imber, eds.

1995 Studying elites using qualitative methods. Thousand Oaks, Calif ; London: Sage.

Hill, James O., Holly R. Wyatt, and Edward L. Melanson

2000 GENETIC AND ENVIRONMENTAL CONTRIBUTIONS TO OBESITY. *Medical Clinics of North America* 84(2):333-346.

Hirst, Paul, and Grahame Thompson

2005[1996] Globalisation in Question: The International Economy and the Possibilities of Governance. Cambridge: Polity Press.

Hogle, Linda F.

1996 Transforming "Body Parts" into Therapeutic Tools: A Report from Germany. *Medical Anthropology Quarterly* 10(4):675-682.

—

2005 *Enhancement Technologies and the Body*. *Annual Review of Anthropology* 34(1):695-716.

Hollis, Martin

1968 Reason and Ritual. *Philosophy* 43(165):231-247.

—

1994 The philosophy of social science : an introduction. Cambridge [England] ; New York, NY, USA: Cambridge University Press.

Honkasalo, Marja-Liisa

2001 Vicissitudes of pain and suffering: Chronic pain and liminality. *Medical Anthropology: Cross-Cultural Studies in Health and Illness* 19(4):319 - 353.

Hont, Gabor, Roger Höglund, and Ulrice Klettner

2007 Hjärtrappporten 2006-2007: En årsrapport från Hjärt-Lugnfonden.

Hornborg, Anne-Christine

2005a *Eloquent Bodies: Rituals in the Contexts of Alleviating Suffering*. *Numen* 52:356-394.

—

- 2005b *Ritualer: Teorier och tillämpning*. Lund: Studentlitteratur.
- , ed.
 2010 *Den rituella människan: Flervetenskapliga perspektiv*
 Linköping: Linköping University Electronic Press.
- Humphrey, Caroline, and James Laidlaw
 1994 *The archetypal actions of ritual : a theory of ritual
 illustrated by the Jain rite of worship*. Oxford: Clarendon Press.
- Hunt, Sharon Ann, et al.
 2005 ACC/AHA 2005 Guideline Update for the Diagnosis and
 Management of Chronic Heart Failure in the Adult--Summary
 Article: A Report of the American College of
 Cardiology/American Heart Association Task Force on Practice
 Guidelines (Writing Committee to Update the 2001 Guidelines
 for the Evaluation and Management of Heart Failure):
 Developed in Collaboration With the American College of Chest
 Physicians and the International Society for Heart and Lung
 Transplantation: Endorsed by the Heart Rhythm Society.
Circulation 112(12):1825-1852.
- Hydén, Lars-Christer
 1997 *Illness and narrative*. *Sociology of Health & Illness*
 19(1):48-69.
- Høystad, Ole M.
 2007 *A History of the Heart*. London: Reaktion Books.
- Ibn Sina, Abu Ali al-Husayn ibn Abd Allah
 1999[1025] *The Canon of Medicine*. Chicago: Great
 Books of the Islamic World, Inc.
- .
- Jackson, Michael
 2010 *From Anxiety to Method in Anthropological Fieldwork: An
 Appraisal of George Devereux's Enduring Ideas*. *In Emotions in
 the Field: The Psychology and Anthropology of Fieldwork
 Experience*. J. Davies and D. Spencer, eds. Stanford, Calif.:
 Stanford University Press.
- Jonvallen, Petra
 2010 *Emotion Work, Abjection and Electronic Foetal
 Monitoring*. *In Technology and Medical Practice: Blood, Guts and
 Machines*. E. Johnson and B. Berner, eds. Farnham, Surrey:
 Ashgate Publishing Limited.
- Joralemon, Donald

- 1995 *Organ Wars: The Battle for Body Parts*. Medical Anthropology Quarterly 9(3):335-356.
- Katz, Pearl
1981 Ritual in the Operating Room. Ethnology 20(4):335-350.
- 1999 *The Scalpel's Edge: The Culture of Surgeons*. Boston, Massachusetts: Allyn and Bacon.
- Kaufman, S. R., et al.
2011 Ironic technology: Old age and the implantable cardioverter defibrillator in US health care. Social Science and Medicine 72(1):6-14.
- Kaufman, Sharon R.
2009 Making Longevity in an Aging Society: Linking Ethical Sensibility and Medicare Spending. Medical Anthropology 28(4):317-325.
- 2010 Time, clinic technologies, and the making of reflexive longevity: the cultural work of time left in an ageing society. Sociology of Health & Illness 32(2):225-237.
- Kaufman, Sharon R., and Lakshmi Fjord
2011 Medicare, Ethics, and Reflexive Longevity: Governing Time and Treatment in an Aging Society. Medical Anthropology Quarterly 25(2):209-231.
- Kaufman, Sharon R., and Lynn M. Morgan
2005 The Anthropology of the Beginnings and Ends of Life. Annual Review of Anthropology 34(1):317-341.
- Koenig, Barbara A., and Linda F. Hogle
1995 Organ Transplantation (Re)Examined? Medical Anthropology Quarterly 9(3):393-397.
- Kondo, Dorinne
1985 The Way of Tea: A Symbolic Analysis. Man 20(2):287-306.
- Kreinath, Jens, Joannes Augustinus Maria Snoek, and Michael Stausberg
2006 *Theorizing rituals*. Leiden: Brill.
- Kucukkömürler, Saime, and Leyla Özgen
2009 Coffee and Turkish Coffee Culture. Pakistan Journal of Nutrition 8(10):1693-1700.
- La Barre, Weston
1967 Preface. *In* From Anxiety to method in the behavioral sciences. Pp. vii-x. New York: Humanities Press.
- Latour, Bruno, and Steve Woolgar

- 1979[1986] Laboratory life : the construction of scientific facts. Princeton, N.J.: Princeton University Press.
- Leach, Edmund R
1968 Ritual. *In* International Encyclopedia of Social Sciences. Pp. 520-526.
- Lee, D. S.
2001 The morning tea break ritual: A case study. *International Journal of Nursing Practice* 7(2):69-73.
- Lévi-Strauss, Claude
1966 The Savage Mind. Chicago: Univ. of Chicago Press.
- Lietz, Katherine MD, PhD; Long, James W. MD, PhD; Kfoury, Abdallah G. MD; Slaughter, Mark S. MD; Silver, Marc A. MD; Milano, Carmelo A. MD; Rogers, Joseph G. MD; Naka, Yoshifumi MD, PhD; Mancini, Donna MD; Miller, Leslie W. MD
2007 Outcomes of Left Ventricular Assist Device Implantation as Destination Therapy in the Post-REMATCH Era: Implications for Patient Selection. *Circulation* 116(5):497-505.
- Liotta, Domingo, et al.
1963 Prolonged assisted circulation during and after cardiac or aortic surgery: Prolonged partial left ventricular bypass by means of intracorporeal circulation. *The American Journal of Cardiology* 12(3):399-405.
- Little, Miles, et al.
1998 Liminality: a major category of the experience of cancer illness. *Social Science & Medicine* 47(10):1485-1494.
- Lloyd-Jones, Donald, et al.
2010 Heart Disease and Stroke Statistics--2010 Update: A Report From the American Heart Association.
- Lock, Margaret
1995 Transcending Mortality: Organ Transplants and the Practice of Contradictions. *Medical Anthropology Quarterly* 9(3):390-393.
- 1996 Death in Technological Time: Locating the End of Meaningful Life. *Medical Anthropology Quarterly* 10(4):575-600.
- 1998 Deadly Disputes: Hybrid Selves and the Calculation of Death in Japan and North America. *Osiris* 13:410-429.
-

2002 *Twice dead : organ transplants and the reinvention of death*. Berkeley: University of California Press.

—

2004 *Living Cadavers and the Calculation of Death*. *Body & Society* 10(2-3):135-152.

Lock, Margaret, and Christina Honde

1990 *Reaching Consensus About Death: Heart Transplants and Cultural Identity in Japan*. *In Social Science Perspectives on Medical Ethics*. G. Weisz, ed. Pp. 99-119. Dordrecht: Kluwer Academic Publishers.

LoveToKnow

2010 *YourDictionary*.

MacPhee, Marybeth

2003 *Medicine for the Heart: The Embodiment of faith in Morocco*. *Medical Anthropology* (22):53-83.

Malinowski, Bronislaw

2002[1922] *Argonauts of Western Pacific: An Account of Native Enterprise and Adventure in the Archipelagoes of Melanesian New Guinea*. London: Routledge.

Marcus, George E.

1995 *Ethnography in/of the World System: The Emergence of Multi-Sited Ethnography*. *Annual Review of Anthropology* 24:95-117.

Masana, Lina

2010 *Invisible chronic illnesses inside apparently healthy bodies*. *In Of Bodies and Symptoms: Anthropological perspectives on their social and medical treatment*. S. Fainzang and C. Haxaire, eds. Tarragona: Publications URV.

Mathers, Colin , Ties Boerma, and Doris Ma Fat

2008 *The global burden of disease: 2004 update*. D.o.H.S.a. Informatics.

Mathers, Colin , et al.

2000 *Global burden of ischaemic heart disease in the year 2000*.

Mattingly, Cheryl

2010 *The Paradox of Hope : journeys through a clinical borderland*. Berkeley ; London: University of California Press.

Mauss, Marcel

1997[1923-24] *Gåvan*: Argos.

Maynard, Ronald J.

- 2006 Controlling Death & Compromising Life: Chronic Disease, Prognostication, and the New Biotechnologies. *Medical Anthropology Quarterly* 20(2):212-234.
- McAlister, A, et al.
1982 Theory and action for health promotion illustrations from the North Karelia Project. *Am J Public Health* 72(1):43-50.
- McAllister, James W.
2007 Introduction: Dilemmas in science: what, why, and how. *In Knowledge in Ferment: Dilemmas in Science, Scholarship and Society*. A. in 't Groen, H.J. de Jonge, E. Klasen, H. Papma, and P. van Slooten, eds. Pp. 13-24. Amsterdam: Leiden University Press.
- Mehra, Mandeep R., et al.
2006 Listing Criteria for Heart Transplantation: International Society for Heart and Lung Transplantation Guidelines for the Care of Cardiac Transplant Candidates—2006. *The Journal of heart and lung transplantation : the official publication of the International Society for Heart Transplantation* 25(9):1024-1042.
- Microsoft
2009 Encarta World English Dictionary [North American Edition].
- Miller, Jonathan
2007 The Anatomised Heart: Understanding the Pump. *In The Heart*. J. Peto, ed. New Haven and London: Yale University Press.
- Mol, Annemarie
2007[2002] The Body Multiple: Ontology in Medical Practice. Durham: Duke University Press.
- Moore, Sally Falk, and Barbara G. Myerhoff, eds.
1977 Secular ritual. Assen: Van Gorcum.
- Moreira, Tiago, and Paolo Palladino
2005 Between truth and hope: on Parkinson's disease, neurotransplantation and the production of the 'self'. *History of the Human Sciences* 18(3):55-82.
- Mosterd, Arend, and Arno W Hoes
2007 Clinical epidemiology of heart failure. *Heart* 93(9):1137-1146.
- Moutaud, Baptiste
2011 From the experimental body to the experimental patient. Medical experimentation in neuroscience. *In Of Bodies and*

- Symptoms. S. Fainzang and C. Haxaire, eds. Tarragona: Publicacions URV.
- Moynihan, B. G. A.
1920 The ritual of a surgical operation. *British Journal of Surgery* 8(29):27-35.
- Mumford, Lewis
1986 Mit o mašini II - Pentagon moći. Zagreb: GZH - Graficki Zavod Hrvatske.
- Murphy, Robert F., et al.
1988 Physical disability and social liminality: A study in the rituals of adversity. *Social Science & Medicine* 26(2):235-242.
- Murphy, Robert Francis
1987 *The body silent*. New York: H. Holt.
- Murray, Christopher J. L., et al.
1996 *Global health statistics : a compendium of incidence, prevalence, and mortality estimates for over 200 conditions*. [Cambridge, Mass.]: Published by the Harvard School of Public Health on behalf of the World Health Organization and the World Bank : Distributed by Harvard University Press.
- Nathoo, Ayesha
2007 *The Transplanted Heart: Surgery in the 1960's*. In *The Heart*. J. Peto, ed. Pp. 156-170. New Haven; London
London: Yale University Press;
Welcome Collection.
- Nisbet, Robert A.
1980 *History of the idea of progress*. New York: Basic Books.
- Nissinen, Aulikki, Ximena Berrios, and Pekka Puska
2001 Community-based noncommunicable disease interventions: lessons from developed countries for developing ones. *Bulletin of the World Health Organization* 79:963-970.
- Nordenfelt, Lennart
2010 H-Seminar, Department of Medical and Health Sciences, Division of Health and Society. Linköping.
- Ortner, Sherry B.
1973 On Key Symbols. *American Anthropologist* 75(5):1338-1346.
- 1978 *Sherpas through their rituals*. Cambridge: Cambridge University Press.
- OxfordUniversityPress

- 2010 Oxford Dictionaries Online: Oxford University Press.
- Peirano, Mariza G. S.
 1998 When Anthropology is at Home: The Different Contexts of a Single Discipline. *Annual Review of Anthropology* 27(ArticleType: research-article / Full publication date: 1998 / Copyright © 1998 Annual Reviews):105-128.
- Penley, Constance, Andrew Ross, and Donna Haraway
 1990 Cyborgs at Large: Interview with Donna Haraway. *Social Text* (25/26):8-23.
- Perry, Ralph Barton
 1909 *The Moral Economy*. New York: Charles Scribner's Sons.
- Persson, Jerker, and Martin Stagmo
 2008 *Perssons kardiologi - Hjärtsjukdomar hos vuxna: Studentlitteratur*.
- Pesmen, Dale
 1995 Standing Bottles, Washing Deals, and Drinking "For the Soul" in a Siberian City. *The Anthropology of east Europe review* 13(2):65-74.
- Petersen, Sophie , Mike Rayner, and Jane Wolstenholme
 2002 *Coronary heart disease statistics: heart failure supplement*. U.o.O. Department of Public Health.
- Peterzén, Bengt
 2001 *Management of patients treated with left ventricular assist devices* Medical Dissertation, Department of Medicine and Care, Faculty of Health Sciences, Linköping University.
- Peto, James, ed.
 2007 *The Heart*. New Haven ; London
 London: Yale University Press ;
 Wellcome Collection.
- Petryna, Adriana
 2002 *Life exposed - Biological Citizens after Chernobyl*:
 Princeton University Press
- 2004 *Biological Citizenship: The Science and Politics of Chernobyl-Exposed Populations*. *Osiris* 19(ArticleType: primary_article / Issue Title: Landscapes of Exposure: Knowledge and Illness in Modern Environments / Full publication date: 2004 / Copyright © 2004 The University of Chicago Press):250-265.
- Pierret, Janine

- 2003 *The illness experience: state of knowledge and perspectives for research*. *Sociology of Health & Illness* 25(3):4-22.
- Plough, Alonzo L.
1986 *Borrowed Time: Artificial Organs and the Politics of Extending Lives*. Philadelphia: Temple University Press.
- Puska, Pekka, E. Leparski, and World Health Organization. Regional Office for Europe.
1988 *Comprehensive cardiovascular community control programmes in Europe*. Copenhagen: World Health Organization, Regional Office for Europe.
- Rabinow, Paul
2002 *Midst Anthropology's Problems*. *Cultural Anthropology* 17(2):135-149.
- 2007[1977] *Reflections on fieldwork in Morocco*. Berkeley: University of California Press.
- 2008 *Artificiality and Enlightenment: From Sociobiology to Biosociality*. In *Anthropologies of Modernity*. J.X. Ina, ed. Pp. 179-193: Blackwell Publishing Ltd.
- Rabinow, Paul, and Nikolas Rose
2006 *Biopower Today*. *BioSocieties* 1(02):195-217.
- Raman, Sujatha, and Richard Tutton
2010 *Life, Science, and Biopower*. *Science, Technology & Human Values* 35(5):711-734.
- Rappaport, Roy A.
1999 *Ritual and religion in the making of humanity*. Cambridge: Cambridge University Press.
- Rascal, Dizzee
- Reckwitz, Andreas
2002 *Toward a Theory of Social Practices: A Development in Culturalist Theorizing*. *European Journal of Social Theory* 5(2):243-263.
- Reddy, K Srinath
2002 *Cardiovascular diseases in the developing countries: dimensions, determinants, dynamics and directions for public health action*. *Public Health Nutrition* 5(1a):231-237.
- Reddy, William M.

- 1999 *Emotional Liberty: Politics and History in the Anthropology of Emotions*. *Cultural Anthropology* 14(2):256-288.
- Reeves, Paula M.
2003 *Heart sense : unlocking your highest purpose and deepest desires*. York Beach, ME: Conari Press ; [Enfield : Airlift, distributor].
- Reynolds-Whyte, Susan
1997 *Questioning misfortune : the pragmatics of uncertainty in eastern Uganda*. Cambridge: Cambridge University Press.
- Roback, Kerstin
2006 *Medical device innovation: The integrated process of invention, diffusion and deployment*, Center for Medical Technology Assessment, Department of Health and Society, Linköping University.
- Roche, Brenda, Alan Neaigus, and Maureen Miller
2005 *Street Smarts and Urban Myths: Women, Sex Work, and the Role of Storytelling in Risk Reduction and Rationalization*. *Medical Anthropology Quarterly* 19(2):149-170.
- Rose, Nikolas
2001 *The Politics of Life Itself*. *Theory, Culture & Society* 18(6):1-30.
- 2009 *Normality and pathology in a biomedical age*. *The Sociological Review* 57:66-83.
- Rose, Nikolas, and carlos Novas
2005 *Biological Citizenship*. *In Global assemblages : technology, politics, and ethics as anthropological problems*. A. Ong and S.J. Collier, eds: Blackwell Publishing.
- Rose, Nikolas S.
2007 *Politics of life itself : biomedicine, power, and subjectivity in the twenty-first century*. Princeton ;: Princeton University Press.
- Rothman, Barbara Katz
1986 *Reflections: On hard work*. *Qualitative Sociology* 9(1):48-53.
- Sanders, Tom, and Stephen Harrison
2008 *Professional legitimacy claims in the multidisciplinary workplace: the case of heart failure care*. *Sociology of Health & Illness* 30(2):289-308.
- Schechner, Richard

- 1988 Performance theory. New York ; London: Routledge.
- Scheff, Thomas J., et al.
1977 The Distancing of Emotion in Ritual [and Comments and Reply]. *Current Anthropology* 18(3):483-505.
- Scheper-Hughes, Nancy
2001a *Bodies for Sale – Whole or in Parts* *Body & Society* 7(2-3):1-8.
- 2001b *Commodity Fetishism in Organs Trafficking*. *Body & Society* 7(2-3):31-62.
- Sharp, Lesley A.
1995 Organ Transplantation as a Transformative Experience: Anthropological Insights into the Restructuring of the Self. *Medical Anthropology Quarterly* 9(3):357-389.
- 2000 The Commodification of the Body and its Parts. *Annual Review of Anthropology* 29(1):287-328.
- 2007 *Bodies, commodities, and biotechnologies : death, mourning, and scientific desire in the realm of human organ transfer*. New York: Columbia University Press.
- 2011 The Invisible Woman: The Bioaesthetics of Engineered Bodies. *Body & Society* 17(1):1-30.
- Sherry, John F.
1995 Bottomless cup, plug-in drug: A telethnography of coffee. *Visual Anthropology: Published in cooperation with the Commission on Visual Anthropology* 7(4):351 - 370.
- Shildrick, Margrit
2010 Some Reflections on the Socio-cultural and Bioscientific Limits of Bodily Integrity. *Body & Society* 16(3):11-22.
- Skillington, Tracey
2009 The Barretstown experience: a rite of passage. *Irish Journal of Sociology* 17(2):72-89.
- Smith, Lindsay, and Arthur Kleinman
2010 Emotional Engagements: Acknowledgement, Advocacy, and Direct Action. *In Emotions in the Field: The Psychology and Anthropology of Field Experience*. J. Davies and D. Spencer, eds. Stanford, Calif.: Stanford University Press.
- Socialstyrelsen

2008a Hjärtsvikt - Vetenskapligt underlag för nationella riktlinjer för hjärtsjukvård 2008. Pp. 64: Socialstyrelsen.

—

2008b Nationella riktlinjer för hjärtsjukvård 2008 - Beslutsstöd för prioriteringar. Pp. 276: Socialstyrelsen - The national Board of Health and Welfare.

—

2010a Dödsorsaksstatistik. I.H. Dödsorsaksstatistik. Antal döda, ålder 0-85+, 2010, ed.

—

2010b Operationsstatistik. F.l.o.a.a.e.-. Antal ingrepp, para- eller intrakorporeal VAD, Riket, ålder: 0-85+ ed: Socialstyrelsen.

Sophie Petersen, Mike Rayner, and Jane Wolstenholme

2002 Coronary heart disease statistics: heart failure supplement. U.o.O. Department of Public Health.

Squier, Susan Merrill

2004 Liminal lives: imagining the human at the frontiers of biomedicine. Durham: Duke University Press.

Staal, Frits

1979 The Meaninglessness of Ritual. *Numen: International Review for the History of Religions* 26(1):2-22.

Stewart, Simon, et al.

2001 More 'malignant' than cancer? Five-year survival following a first admission for heart failure. *European Journal of Heart Failure* 3(3):315-322.

Strathern, Andrew, and Pamela J. Stewart

1999 *Curing and healing : medical anthropology in global perspective*. Durham, N.C.: Carolina Academic Press.

Strong, Philip

1979 *The ceremonial order of the clinic : parents, doctors, and medical bureaucracies*. London: Routledge & Kegan Paul.

Sudakov, Monika

2005 *The social significance of mint tea consumption in Morocco: Reflections on its symbolic representation of Muslim faith, gender prescriptions, socio-economics and hospitality*, University of Nevada.

SynCardia Systems, Inc.

2006 Annual report 2007 - A second Chance At Life.

—

2007 Annual report 2007 - A second Chance At Life.

- Tambiah, Stanley Jeyaraja
 1990 *Magic, science, religion, and the scope of rationality.*
 Cambridge: Cambridge University Press.
- Texas-Heart-Institute
 2008 *About us.*
- Thelander, Sabrina
 2001 *Tillbaka till livet : att skapa säkerhet i hjärtintensivvården*
 Dissertation, Arkiv förlag.
- Thrift, Nigel
 2006 *Donna Haraway's Dreams.* *Theory Culture Society* 23(7-8):189-195.
- Toombs, S. Kay
 1993 *The metamorphosis: The nature of chronic illness and its challenge to medicine.* *Journal of Medical Humanities* 14(4):223-230.
- 1995 *The lived experience of disability.* *Human Studies* 18(1):9-23.
- TransplantBuddies
 2012 *Natasha's double lung transplant story, Vol. 2012:*
www.transplantbuddies.org.
- Turner, Bryan S.
 2003 *Social Fluids: Metaphors and Meanings of Society.* *Body Society* 9(1):1-10.
- Turner, Victor
 1968 *The drums of affliction : a study of religious processes among the Ndembu of Zambia.* Oxford
 London: Clarendon Press; International African Institute.
- 1977 *Variations On a Theme of Liminality.* *In Secular Rituals.*
 S.F. Moore and B.G. Myerhoff, eds. Assen: Van Gorcum.
- Turner, Victor
 1973[1967] *The forest of symbols : aspects of Ndembu ritual.* Ithaca: Cornell University Press.
- 1986 *The anthropology of performance.* New York: PAJ Publications.
- 1997[1969] *The Ritual Process - Structure and Anti-Structure.* New York: Aldine De Gruyter.

Ultralingua

2010 Ultralingua Online Dictionary.

UNCTAD

2009 The Least Developed Countries Report 2009 : the state and development governance. 978-92-1-112769-0 (nid.)

0257-7550 ;. United Nations.

University.of.Washington.School.of.Medicine

1998 Ethics in Medicine. D.o.B. Humanity, ed, Vol. 2011: University of Washington.

Waldenström, Anders

2008 Hjärtsvikt - En Temaskrift från Hjärt-Lungfonden. Hjärt-Lungfonden.

van der Geest, Sjaak, and Kaja Finkler

2004 Hospital ethnography: introduction. Social Science & Medicine 59(10):1995-2001.

Van Dongen, Els

1998 Strangers on terra cognita: authors of the Other in a mental hospital. Anthropology & Medicine 5(3):279.

van Gennep, Arnold

1960[1908] The Rites of Passage. M. Vizedom and G.L. Caffee, transl. Chicago: University of Chicago Press.

Vedder, Eddie

2002 Thumbing My Way, seventh track from seventh album, Riot Act, by Pearl Jam: Epic Records.

Wertsch, James V.

2008 The Narrative Organization of Collective Memory. Ethos 36(1):120-135.

Whyte, Susan Reynolds

2009 Health Identities and Subjectivities. Medical Anthropology Quarterly 23(1):6-15.

Wikan, Unni

1989 Managing the Heart to Brighten Face and Soul: Emotions in Balinese Morality and Health Care. American Ethnologist 16(2):294-312.

—

1990 Managing turbulent hearts : a Balinese formula for living. Chicago: University of Chicago Press.

Willett, Jeffrey, and Mary Jo Deegan

- 2001 Liminality and Disability: Rites of Passage and Community in Hypermodern Society. *Disability Studies Quarterly* 21(3):137-152.
- Williams, Simon J.
1998 Modernity and the Emotions: Corporeal Reflections on the (Ir)rational. *Sociology* 32(04):747-769.
- Wilson, Monica
1954a Nyakyusa Ritual and Symbolism. *American Anthropologist* 56(2):228-241.
- Wilson, Robert N.
1954b Teamwork in the Operating Room. *Human Organization* 12(4):9-14.
- von Wright, G. H.
1993 Myten om framsteget : tankar 1987-1992 med en intellektuell sja\0308lvbiografi. [Helsingfors]: So\0308derstro\0308ms.
- Woodward, David, et al.
2001 Globalization and health: a framework for analysis and action. *Bulletin of the World Health Organization* 79:875-881.
- Wulff, Helena
1998 Ballet across borders : career and culture in the world of dancers. Oxford ; New York: Berg.
- Yach, Derek, et al.
2004 The Global Burden of Chronic Diseases: Overcoming Impediments to Prevention and Control. *JAMA* 291(21):2616-2622.
- Young, Louisa
2002 The book of the heart. London: Flamingo.