

EXPLORING THE PSYCHOLOGICAL EFFECTS OF ENDOMETRIOSIS: A  
QUALITATIVE STUDY

by

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I declare that

**Exploring the Psychological Effects of Endometriosis: A Qualitative Study**

is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

.....

SIGNATURE

(Mrs C. J. Bennie)

.....

DATE

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*This dissertation is dedicated to my father, whose gentle and generous spirit is an inspiration to me everyday!*

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## SUMMARY

Endometriosis is a pervasive, widespread disease that affects millions of women worldwide. The number of women affected by endometriosis is increasing at a staggering rate. Endometriosis impacts women in a variety of ways; it often gradually strips away their resistance to pain, their emotional strength, their concept of femininity and their ability to cope with challenges. This study aimed to provide a voice for women diagnosed with endometriosis. The study allowed the participants to share their experiences from diagnosis through to treatment and to explain the ways in which endometriosis influences their daily lives. In this research report the psychological impact of this disease is discussed, and factors that are not currently addressed by medical professionals treating women with endometriosis are highlighted.

Social constructionism provided the theoretical framework for the study. One-on-one, in-depth interviews were conducted with five women who have been diagnosed with endometriosis by a gynaecologist through means of laparoscopic surgery. The method of analysis involved thematic network analysis.

The participants' narratives were converted into interview transcripts. These transcripts were analysed by the researchers and themes were identified. Themes that repeated were elaborated and were linked to available literature.

The researcher hopes that this dissertation will contribute to existing knowledge regarding the psychological effects of endometriosis. It is hoped that it will help both the medical community and future and existing patients understand this disease and the effect that it has on the lives of women around the world, but particularly the lives of women in South Africa.

**Keywords:** chronic pain, social constructionism, dyspareunia, endometriosis, femininity, infertility, postmodernism, psychological effects, relational patterns, sexual dysfunction, stigma, quality of life, health psychology

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## Chapter 1

### INTRODUCTION

*There is probably no other benign condition in gynaecology  
that has remained so long misunderstood, misdiagnosed,  
and refractory to effective obliteration as pelvic endometriosis.*

*(Leventhal in Weinstein, 1982 p. xix)*

#### A Personal Statement

As a woman who has personally suffered with endometriosis for many years, I am a member of two communities: the larger South African female community and the more insular community of women who live with this disease. Being part of the endometriosis community has allowed me to explore my own physical and emotional experiences. It has also led me to question the way in which the medical community addresses this disease. Within the South African context I have come to realise how little exposure or importance is placed on the effects of this disease on women and society in general.

I have personally experienced all the highs and lows related to this disease. This has strengthened my convictions and confidence in my own body, but at times has come close to stripping me of all sanity. The lack of available knowledge has prompted me to stand-up for South African women struggling with this disease and attempt to bring humanity back to this often faceless and clinical disease. However, my experiences have also allowed me to appreciate life, even when faced with adversity. These experiences have allowed me to see the incredible love and support that can be gained from trusted family and partners.

My personal background created the question that served as the point of departure for this research:

How does having endometriosis affect a woman psychologically, and what impact does this have on a woman's life?

Melanie Bates (2010), a fellow endometriosis sufferer and avid blogger, writes:

I usually tell people, strictly out of exhaustion, that it's a "girly" disease. This comes from being raised in a household where you don't talk about stuff like this. If by some circumstance of extreme horror a particularly cute boy asks, I worry that he thinks I have funky bacteria of the hoo-ha and imagine him running home to Google.

Her statement highlights the multi-faceted plight of many women suffering with endometriosis, who so often feel isolated, alone and embarrassed by the disease.

My hope for this research is that in some small way it will encourage women to take ownership of this disease and to step out of the shadows of doubt and awkwardness into the light of self-awareness and acceptance. I hope that this research will also encourage these women to educate others and to demand open communication and medical advances. In addition, I hope to highlight to the medical community the importance of treating women holistically as consisting of both physical and psychological beings.

### **General Introduction**

Endometriosis is the second most commonly experienced gynaecological condition, affecting an estimated 77 million women worldwide (Pharmasave Library, 2010). Recent literature suggests that approximately 30-40% of all infertile women have some degree of endometriosis (Nezhat, 2008).

The increasing number of women in the workforce has led to women's health becoming a key societal focus area, with primary emphasis being placed on medical conditions. However, this focus often negates the emotional aspects that accompany most medical conditions. Many women diagnosed with endometriosis experience a roller-coaster of emotions due to the associated pain, tiredness, hormonal fluctuations, lack of support from partners or family and the likelihood of infertility.

Medical professionals frequently focus on infertility as the major, and often only, symptom of endometriosis. However, endometriosis is actually a multi-faceted problem. A diagnosis of endometriosis is often accompanied by grief-like symptoms (Fernandez, Reid, & Dziurawiec, 2006) including shock, disbelief, frustration, anger, isolation, powerlessness, depression and, finally, acceptance. Other common symptoms include sexual dysfunction, chronic pain, fatigue and lack of self-esteem (Jones, Jenkinson, & Kennedy, 2004).

According to The American College of Obstetricians and Gynaecologists (2010) conservative non-surgical treatment is recommended to alleviate pain resulting from endometriosis. This treatment includes the use of continuous oral contraceptives and non-steroidal anti-inflammatory drugs. However, if these first line treatments fail more invasive approaches are used, including laparoscopic surgery and hysterectomies. The complex nature of endometriosis has given rise to a large number of misconceptions and myths relating to the disease. Many doctors still believe that endometriosis is rare in teenagers and young women or that pregnancy cures endometriosis (Wood, 2010). These myths often have far reaching consequences for the patients, leading to misdiagnosis of young women by ignorant doctors. It is particularly concerning that women are being encouraged to have children before they are emotionally ready for the responsibility, thus placing unnecessary strain on their relationships. “The thing I found most frustrating was my doctor telling me to get pregnant – and I’m single” (Weinstein, 1992, p. 93).

Most women receive treatment for the symptoms of endometriosis. These treatments usually include painkillers and a variety of hormone therapies. However, the treatment of endometriosis is not as easy as simply reducing pain and removing cysts or endometrial tissue. Research has found that women with endometriosis are at high risk for osteoporosis, cancer, depression and migraines (Cox, Ski, Wood, & Sheahan, 2003). It is thus vital that both patients and medical professionals fully grasp the variety of ways in which endometriosis can influence sufferers’ lives. These various effects need to be addressed on a continual basis throughout a woman’s life, as the effects of endometriosis differ at various life stages.

Holistic treatment for endometriosis should include consideration of alternative therapies such as reflexology, massage and diet to complement the regular medical

treatment. Doctors should also reassure patients that psychological issues relating to chronic pain and infertility are normal. Patients need to be referred to complementary medical services such as psychologists and support groups. Being able to talk about their problems often proves very cathartic for these women.

It is important to remember that endometriosis has an impact on a patient's partner and family. This means that a woman should never be treated in isolation but should always be regarded as part of a complex system consisting of multiple members with various emotional and psychological needs.

### **Explaining the Title**

The title of this study "*Exploring the Psychological Effects of Endometriosis: A Qualitative Study*" points to the essence of the study: an exploration of the psychological experiences of endometriosis sufferers. Endometriosis is a multi-dimensional disease that impacts on various aspects of life. In addition to significant emotional distress, endometriosis sufferers also report difficulty with interpersonal relationships, sexual dysfunction, chronic pain, increased stress levels, changes in self-identity and lowered self-esteem (Andersen, 1984).

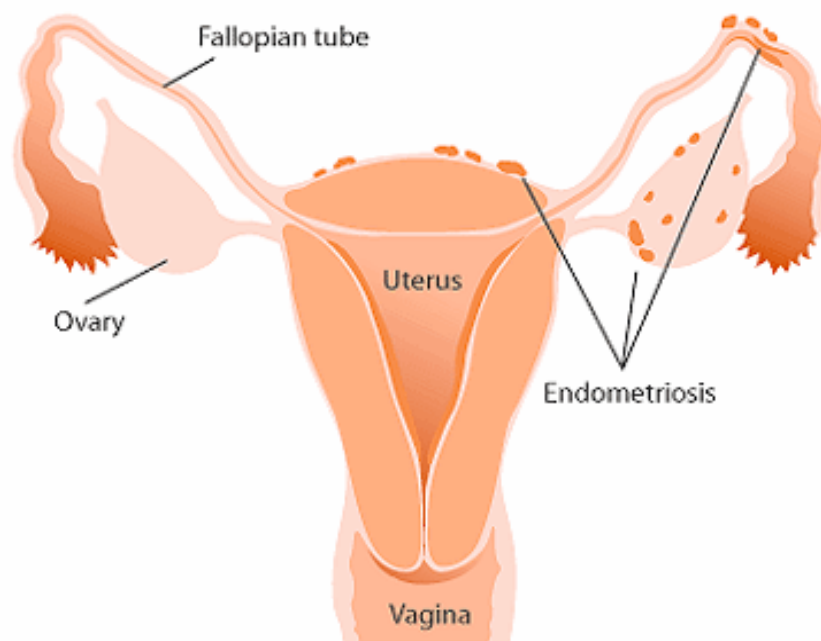
In this research study five women share their stories. The women all have different and unique experiences, but their worlds are connected by the occurrence of endometriosis. Through the study these women were given the opportunity to give voice to their stories. The objectives of the study included understanding the meanings these women hold in relation to personal suffering, the nature of endometriosis and the variety of ways of coping with the disease.

### **Rationale**

Endometriosis is a chronic, progressive disease generally associated with pain, infertility and psychological difficulties. Psychosocial factors that impinge on sufferers include the inability to work or participate in leisure activities due to pain, strain on relationships due to sexual dysfunction, identity issues and diminished self-esteem. Endometriosis is linked to issues such as menstruation, sex, infertility and

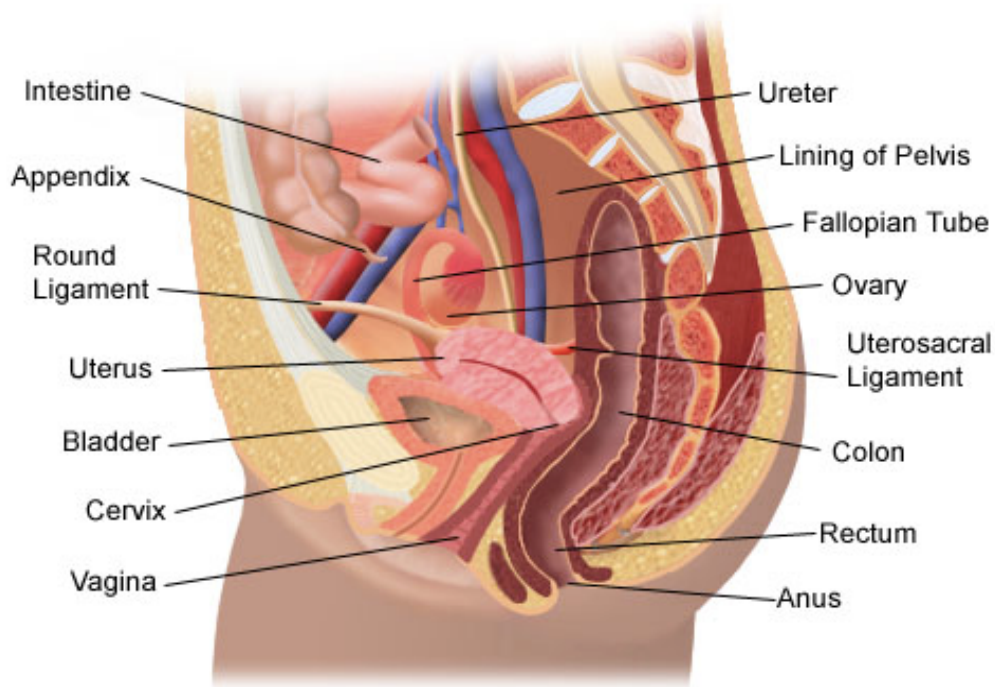
pain, which are generally considered taboo subjects in South Africa. The taboo nature of these topics leads to misunderstanding and miscommunication of information in the general public.

The exact cause of endometriosis is unknown, although it has been linked to genetic factors, issues of immunity and transplantation. Endometriosis is defined as the presence of endometrial tissue outside its normal location as the lining of the uterus (Isaacson, 1995). It typically affects organs in the pelvic area such as the bladder, colon, ovaries, fallopian tubes, the uterus and the gastrointestinal system, as seen in Figures 1.1 and 1.2.



*Figure 1.1.* Female Anatomy relating to Endometriosis (Lavelle, 2007)





*Figure 1.2.* Possible sites of Endometriosis in the pelvic area (Endometriosis Resolved, 2010)

I have first hand knowledge of the various dimensions of life impacted by endometriosis. In the eight years since my diagnosis I have had the opportunity to meet a number of women who suffer from endometriosis and other gynaecological diseases. A common thread between these women is often the lack of emotional support they receive from the medical community.

My research has made it apparent that the medical system in South Africa is failing patients in addressing the treatment options and awareness of endometriosis. Patients have lost confidence in the health care system and feel that general practitioners and gynaecologists lack sufficient training with regards to endometriosis. Unlike its counterparts in the USA, United Kingdom and Australia, the South African government does not fund any research or public campaigns relating to endometriosis education.

Because women with endometriosis often appear healthy externally they frequently experience lack sympathy or understanding from others. Society repeatedly fails to understand the long term consequences of endometriosis, not only for its sufferers but

also for the economy due to reduced ability to be productive, time spent away from work and costs to the private or public health sector for surgery and medications (Knight, 2006). For women diagnosed with infertility, the costs associated with in-vitro fertilization (IVF) treatments can place extreme strain on patients and their partners or families. These costs ultimately have a knock on effect on the country's economy.

There are very few endometriosis support groups in South Africa. Those groups that do exist focus predominantly on the issue of infertility, an issue that is not likely to be of concern to the growing number of young women suffering from endometriosis. These young women are therefore unlikely to seek membership in these existing support groups.

The medical community regularly overlooks the use of alternative therapies as aids in the treatment of endometriosis. These therapies include the use of diet to control symptoms, reflexology to facilitate stress relief and consultation with psychologists to help women deal with the complexity of their disease and its impact on their lives.

It is important for physicians to acknowledge the feelings of fear, frustration, anger and confusion that accompany the experience of endometriosis, and to make sure that these are treated as normal aspects of the disease. This allows women suffering with endometriosis to feel less isolated or ostracized and to feel that their experiences are acceptable. Through understanding the nature of the suffering health care professionals may be able to provide appropriate assistance to women in terms of counselling and appropriate holistic treatments.

Because endometriosis highlights topics usually considered taboo, such as menstruation and sexual dysfunction (Hummelshøj, 2005), women frequently feel embarrassed and are unable to share their experiences with others. This can cause strain in relationships as they carry the burden of their disease with little understanding from the general public. Educating the public and key stakeholders is paramount in ensuring an empirical understanding of the disease. Only once the facts are understood can reassurance and emotional support be offered. In this way a woman's individual experience of endometriosis can be validated.

## **Research Aims**

Living with endometriosis is complex and hence it is important to not impose value judgements on individuals' experiences of this disease. This research is grounded within a social constructionist theoretical framework, which allows the story of each participant to be placed in context. Within this research the researcher acknowledges her own personal views, while creating a space for dialogical conversation.

The main objective of this research study was to explore and describe the psychological effects that patients with endometriosis experience within the South African context through the use of qualitative and narrative interviews.

The aims of this research were as follows:

- To communicate a depth of understanding on the topic of endometriosis for interested parties.
- To make use of in-depth interviews to shed light on individual experiences of endometriosis and the ways in which the disease impacts lives.
- To explore the impact of the disease on the psychological aspects of participants' lives.

This research gives a voice to women who suffer with endometriosis, many of whom often feel alienated or misunderstood. These narratives of personal experience may help guide the development of information for patients diagnosed with this disease. It may also create awareness surrounding the often-neglected psychological effects of this disease. Finally, it is hoped that the information obtained in this study will help therapists and medical professionals more fully understand the problems facing patients with endometriosis.

## **Design of Inquiry**

Research in healthcare is traditionally strongly rooted in modernism (Walker, Payne, Smith, & Jarrett, 2007). This has created a divide between physical treatment and social support. The current literature suggests that although the positivist approach is

still dominant within the medical field, there is emerging interest in alternative ways of exploring chronic illness, with specific reference to endometriosis (Cox, et al., 2003; Graziottin & Leiblum, 2005; Strzempko Butt & Chesla, 2007). Much of the previous research on endometriosis has been quantitative in nature, using questionnaires relating to quality of life, depression and symptoms of endometriosis. The personal narratives of the women living with the disease have been neglected. This study's exploration of the effects of endometriosis on women and their lives adds another voice to the plea for the holistic and comprehensive treatment of endometriosis within the current healthcare system.

Social constructionism serves as the epistemological framework for this study. Social constructionism is concerned with understanding how people come to describe, explain and account for their world (Gergen, 1985). It allows for personal accounts or stories that are based on unique and individual experiences (Viviers, 2005). Social constructionism and postmodernism are discussed further in chapter 3.

A qualitative approach was used; this approach is consistent with the overall aim and rationale of the study. The qualitative methodology allowed the creation of an in-depth and rich understanding of the psychological effects of endometriosis through the 'voices' of the participants. Qualitative research often uses empathy with participants as a strategy of observation. This empathic understanding draws on the researcher's own experiences and self-knowledge, the meanings co-created within a community and the participants' language and behaviour (Stiles, 1993).

The interviews were conducted in a conversational manner, thus allowing for a free exploration of endometriosis and its impact on the women's lives. The participants were given the chance to think about the impact of endometriosis on their lives and give voice to the experiences, both good and bad, without feeling judged or imposed upon. The participants were considered authorities on their own stories. The researcher's role was to know with others rather than about them (Bhana, 2006). This was achieved by displaying an inquisitive demeanour instead of representing the participants as objects of investigation.

Following the conversations with the participants, the researcher reconstructed their stories in terms of themes. The themes are discussed separately and are linked to relevant literature. It must be acknowledged that my (the researcher's) interpretations of these stories is coloured by my own realities at that specific point in time. Thus, the final presentation of themes and the comparative analysis of the themes represent a co-construction between the researcher's reality, the participants' reality and the literature. The research design does not allow for the findings to be generalized to a larger population, but aims to contribute to the understanding of endometriosis and the struggles that women living with this disease face. Specific information regarding sampling, data collection and data analysis is provided in chapter 3.

*Table 1.1. Biographical information for the participants involved in the study*

<i>Biographical information relating to the five participants in the study</i>	
<b>Charlene</b>	
Age	30
Marital Status	Married, three year old daughter and currently pregnant
Ethnic Origin	Indian
Diagnosed	2003
No. of operations	1 Laparoscopic surgery
<b>Anne</b>	
Age	49
Marital Status	Married with two daughters
Ethnic Origin	Caucasian
Diagnosed	2000
No. of operations	2 Laparoscopic surgeries
<b>Estelle</b>	
Age	23
Marital Status	In a relationship
Ethnic Origin	Caucasian
Diagnosed	2010
No. of operations	1 Laparoscopic surgery

**Kaitlyn**

Age	21
Marital Status	Single
Ethnic Origin	Caucasian
Diagnosed	2005
No. of operations	2 Laparoscopic surgeries

**Phillippa**

Age	34
Marital Status	Married with no children
Ethnic Origin	Caucasian
Diagnosed	1999
No. of operations	+/- 25 Laparoscopic surgeries

---

**The Format of the Study**

This study involved both theoretical and practical components. The theoretical component is presented in this research report in the form of a literature review and a discussion of the theoretical framework of the study and the research methods employed. The methods were chosen in accordance with the theoretical framework.

The literature review in this study explores the concept of endometriosis with specific focus on the experiences of partners and the various psychological effects experienced by women living with endometriosis. This literature review provides background for the research study and positions the study in the context of endometriosis research. Incorporating different 'voices' in the exploration of the psychological effects of endometriosis links to the postmodern and social constructionist premise of the existence of multiple realities.

The practical component of the research provided five women diagnosed and living with endometriosis an opportunity to tell their stories. The accounts were then deconstructed into themes and compared. These women's voices are added to the voices in the literature and provide narratives of unique and personal experiences.

Ultimately, the exploration of the psychological effects of endometriosis involves the co-construction of the participants' stories, the literature and the researcher's reality.

### **The Presentation of the Study**

This study is divided into six chapters.

**Chapter 2** contains the literature review. A general introduction grounds the reader in an understanding of endometriosis and includes definitions of the relevant terminology from both the medical and patient perspectives. The chapter also reports on previous research and the documented effects of endometriosis. Simultaneously, the chapter connects research on the effects of living with other chronic illnesses to the effects of living with endometriosis. Finally, the experience of partners of women diagnosed with endometriosis is explored in terms of the illness experience.

**Chapter 3** discusses the theoretical and methodological approaches of the study. Postmodernism is discussed as the broader research philosophy, while social constructionism is discussed as the selected epistemological stance. The chapter then focuses on different aspects of the qualitative research methodology used in the study. The chapter concludes with a discussion of the research design, research process, participant information and data analysis.

**Chapter 4** presents a deconstruction of each participant's story in terms of the themes that emerged. One of the transcribed interviews is attached as appendix D.

**Chapter 5** involves a comparative analysis of the participant's stories and the literature. This chapter is designed to allow the reader to infer personal distinctions and meanings.

**Chapter 6** concludes the research. The strengths and limitations of the study are evaluated and recommendations for future research are made.

## **Conclusion**

Very little attention has been paid to the personal experiences of women with endometriosis; much of the existing literature concerning the disease relates simply to epidemiology. This study attempts to address this shortcoming by giving a 'voice' to women suffering from this disease and highlighting the need for comprehensive and holistic treatment plans. In Chapter 2 the literature review will be presented.



## **Chapter 2**

### **LITERATURE REVIEW**

#### **Introduction**

In order to explore the psychological effects of endometriosis it is vital that the concept of endometriosis is understood. This chapter provides definitions for and explanations of various key concepts vital to this study. It begins by providing definitions of endometriosis from the viewpoints of both patients and clinicians. The discussion then focus on the symptomology and the treatment options currently available. This is followed by a discussion of the available literature relating to the psychological effects of this disease and the experience of women living with endometriosis. The final section of the chapter focuses on the experiences of partners living with women who suffer with endometriosis.

#### **Endometriosis Explained**

Endometriosis is defined as the presence of endometrial tissue outside the endometrial cavity and uterine musculature (Isaacson, 1995). This misplaced tissue takes the form of lesions, implants, nodules and cysts (Weinstein, 1992). These remain in the pelvic cavity and inflame surrounding tissue, leading to the formation of scar tissue and adhesions, which spin webs among the pelvic organs and mat them together in unnatural formations that may interfere with normal functioning (Weinstein, 1992). Endometriosis typically impacts the organs and structures of the pelvis, which include the ovaries, the uterus, the fallopian tubes, the bladder, the colon, the lining of the pelvic cavity and the gastrointestinal system. In a few cases endometrial tissue has been found in the lungs and other organs of the body (Weinstein, 1992). Endometriosis is sometimes referred to as a ‘benign cancer’ (Weinstein, 1992, p. 22) as it shares certain characteristics with cancer; it has the capacity to proliferate, to metastasize and to invade and penetrate organs. However, unlike cancer it does not consume the organs it affects but merely compresses them, pushes them aside or surrounds them.

Bates (2010) provides the following explanation of endometriosis from the point of view of an endometriosis sufferer:

We sufferers would not say, ‘endometrial lining has moved into our bowels.’ Those of us ‘blessed’ by it would NOT say, ‘endometriosis causes painful intercourse.’ Rather we would calmly ask our partners to ‘put that thing back immediately,’ or say, ‘I’ve made up the bed in the guest room.’ (p. 2)

The prevalence of endometriosis ranges from 1% to 50% based on the indication for surgery, however many cases may not warrant surgery and are thus excluded from these statistics. Endometriosis is found in 30-40% of women with infertility and in up to 65% of women with chronic pelvic pain (Isaacson, 1995). Endometriosis crosses all socioeconomic and cultural barriers. The exact prevalence of endometriosis is not known because it can only be diagnosed through direct visualization or biopsy. According to Isaacson (1995), early data suggested that the disease was more prevalent in women of higher socioeconomic status. However, this assumption was flawed as many women in lower socioeconomic brackets remained undiagnosed because they had no access to qualified gynaecologists and no medical insurance and were thus unable to afford the surgical exploration needed for diagnosis.

Endometriosis is a chronic, progressive and enigmatic disease that affects sufferers’ emotional well-being and physical health. Sufferers experience symptoms such as pelvic pain, sexual dysfunction, infertility and other psychological conditions. Approximately 75% of all patients are aged between 30 and 40 years. It is estimated that between 30 and 40% of endometriosis sufferers experience infertility (Low, Edelmann, & Sutton, 1993). Further psychosocial factors that impinge on sufferers include the inability to work or participate in leisure activities due to pain, strain on relationships due to sexual dysfunction, identity issues and diminished self-esteem.

The exact cause of endometriosis is not known, but it seems likely that the disease has a multi-factorial origin. According to Cox et al. (2003, p. 200) endometriosis is referred to as the “disease of theories” (p.200) because of the proliferation of causation theories. One of the most popular causation theories involves retrograde (or reverse) menstruation. This theory suggests that during menstruation blood is carried

to the pelvis and fallopian tubes rather than out of the vagina. This endometrial tissue then implants on surfaces. A lowered immune system may contribute to the persistence of the implants (Wellbery, 1999). Another popular theory suggests that tissue within the epithelium can be transformed into endometrial tissue, possibly due to chronic inflammation or chemical irritation. This theory of is known as coelomic metaplasia (Wellbery, 1999, p. 2) and may account for the presence of endometriosis in the lungs or other organs outside of the pelvic region.

There is also good evidence that genetics play an important role in endometriosis (Cramer & Missmer, 2002; Kennedy & Parkes, 2000). Isaacson (1995) reports that first-degree female relatives of women with endometriosis have a sevenfold increased risk of developing endometriosis.

The symptomatology of endometriosis is extremely inconsistent and symptoms can be vague or specific, mild or acute, intermittent or continuous. In fact, as many as one-third of all women with the disease may be asymptomatic (Weinstein, 1992). The amount of endometriosis present does not correlate to the severity of the symptoms (Isaacson, 1995). This variability can lead to patients not being diagnosed or being misdiagnosed.

Symptoms include:

- Infertility
- Pelvic pain
- Backache
- Menstrual disorders
- Dysmenorrhea
- Spontaneous abortion
- Ectopic pregnancy
- Nausea & vomiting
- Abdominal cramping
- Rectal pain
- Diarrhoea or constipation
- Hypertension
- Headache
- Excessive fatigue

- Depression and anxiety
- Dyspareunia

(Cox, et al., 2003; Weinstein, 1992; Wellbery, 1999)

The primary symptoms of endometriosis are dysmenorrhea, infertility, generalized pelvic or back pain and dyspareunia. A 1998 study by the Endometriosis Association of American involving 4000 women with endometriosis found that 95% suffered from dysmenorrhea, 87% experienced fatigue and approximately 85% of respondents suffered diarrhoea or other intestinal upsets during their periods (Ballweg, 2004). The study also found that 57% of the respondents reported allergies, particularly to pollens, dust, fragrances, foods and cleaning products (Ballweg, 2004). Pain during or after sex was significantly greater in women who first experienced symptoms before age 25. This finding led Ballweg (2004) to conclude that failure to diagnose and treat endometriosis early is likely to result in experiences of extreme pain in later years.

Dysmenorrhea refers to severe pain in relation to menstruation (Rees, 2000).

Dysmenorrhea is usually experienced in the form of cramps but has been associated with a number of other symptoms including nausea, dizziness, vomiting, diarrhoea, backache, headaches and, occasionally, fainting (Weinstein, 1992). Pain is always subjective and the variations in individual tolerance make it difficult for women and doctors to distinguish between normal menstrual discomfort and pain that is indicative of endometriosis. Many women do not tell their doctors about menstrual pain, due to a belief that menstrual pain is normal and/or untreatable (Weinstein, 1992). Regrettably, women's health is often jeopardised by resignation and denial. Women are often willingly to accept pain as a normal by-product of 'female troubles'. However, although pain and discomfort are commonplace they are not normal (Weinstein, 1992) and women should not be expected to simply endure pain and discomfort. Weinstein (1992) notes that women often fear that gynaecological problems will be perceived as an Achilles heel, or as further support for gender role prejudices that perpetuate stereotypes of women as frail and inferior. The only way to overcome these stereotypes is to confront the myths and taboos surrounding gynaecological disease and to stimulate research into the topic. Attention must be paid to these genuine issues that confront women on a daily basis.

Dyspareunia refers to pain during, or in association with, sexual intercourse (Dodd & Parsons, 1984; Hawton & Harrison, 2000). Dyspareunia is variable, unpredictable, emotionally devastating and physically excruciating (Weinstein, 1992). The pain has been described as ranging from a sharp, stabbing, jab to a deep ache (Johnson, 2003) and can sometimes be felt for up to 48 hours after intercourse. The experience of pain eats away at a woman's sexual self-esteem and can create strain in relationships. Open and honest communication within a couple is required in order to deal with painful intercourse. Partners need to be aware of each other's predicament and feelings (Johnson, 2003). Concealment of the pain can lead to emotional withdrawal, which can be perceived as rejection, thus placing unnecessary stress on the relationship.

Endometriosis is also commonly associated with generalized pelvic pain. This pain is often the initial symptom of the disease. However, the pain then becomes chronic, outliving its usefulness as a warning symptom and begins to encroach on all facets of life (Lemaire, 2004). It produces anxiety, prolonged stress, depression and despair (Weinstein, 1992).

The suffering experienced as a result of endometriosis is invisible and is often discredited by society (Whelan, 2007). Drugs can bring some symptomatic relief, but long-term drug use has its own risks and complications, particularly in terms of organ damage and addiction. In order to adequately control the pain and its effects, doctors and women with endometriosis need to investigate a comprehensive treatment plan focusing on problems associated with chronic pain rather than treatment plans formulated for managing acute pain.

### **Risk Factors and Epidemiological Findings**

Research undertaken by Cramer and Missmer (2002) suggests that adolescents with intractable dysmenorrhea or pelvic pain are at considerable risk for endometriosis. According to the study approximately 50% of these adolescents are diagnosed with endometriosis (Cramer & Missmer, 2002).

Dysmenorrhea is strongly associated with risk for endometriosis, although it is often interpreted as a symptom of the disease. There is also strong evidence that women

with endometriosis are likely to have a first-degree female relative (mother or sister) with the disease. Alcohol and caffeine use also increase the risk of endometriosis (table 2.1) by increasing estrogen levels. Conversely, cigarette smoking lowers estrogen levels and is associated with a decreased risk of endometriosis. Table 2.1 provides a summary of the risk factors investigated by Cramer & Missmer (2002).

*Table 2.1.* Summary of risk factors for endometriosis (Cramer & Missmer, 2002)

Variable	Description of Association
Age of menarche	Early age menarche fairly consistently found to increase risk
Cycle length	Shorter, more regular cycles fairly consistently increase risk
Dysmenorrhea	Strong predictor, but assumed to be a symptom of existing disease
Parity	Decreasing risk with higher parity
Weight, BMI	Weak inverse association
Height	Taller height increases risk
Exercise	Regular exercise may decrease risk
Smoking	Smoking may decrease risk
Alcohol	Use may increase risk
Caffeine	Use may increase risk
Family history	Strong evidence that family history increases risk

### **Management Options**

A confirmed diagnosis of endometriosis can only be made based on visual inspection of the pelvis through laparoscopic surgery. However, the accuracy of diagnostic surgery is dependent on the experience of the gynaecologist, the quality of equipment and the thoroughness of the examination (Kennedy & Parkes, 2000).

The treatment for endometriosis includes surgical or medical intervention or a combination of the two. Expectant management is also used as a treatment option. Treatment plans are usually symptom based and clinicians tend to address symptoms as they arise in order to avoid subjecting patients to medical or surgical treatments that are deemed unnecessary. Approximately 20-40% of patients with moderate endometriosis will eventually develop severe endometriosis (Isaacson, 1995). Clinicians are currently unable to predict which asymptomatic patients require preventative treatment in order to delay future progression of the disease.

Expectant therapy involves a period of observation and minimal medical intervention (Weinstein, 1992). This form of intervention is generally used for women who have mild symptoms, for younger women who have no immediate desire to conceive and older women nearing menopause. The treatment involves prescription of mild analgesics, non-steroidal anti-inflammatory agents, tranquilizers and anti-depressants. Follow-up and feedback play an important role in expectant therapy (Weinstein, 1992). The clinician needs to be able to determine the effectiveness of the approach and to monitor the condition on a regular basis. If the approach does not provide adequate relief, or if the condition worsens, then further medical or surgical intervention is recommended. Expectant therapy does help to reduce patients' symptoms but it does not address the cumulative effect of the disease. Clinicians need to make sure that women are aware of the potential risks and side effects associated with the various drugs. A more comprehensive approach needs to be developed that addresses not only the treatment of the symptoms, but also assists women in improving their general health, exploring their emotional reaction to endometriosis and recognising the ways in which pain affects their lives (Weinstein, 1992).

Hormone therapy is widely used in the treatment of endometriosis as it leads to a regression or atrophy of the endometrium (Weinstein, 1992). This is not a cure but does provide temporary relief from the symptoms. Gynaecologists often place younger women, who do not wish to conceive immediately, on the cyclical use of oral contraceptives. Continual use of oral contraceptive pills, also known as the pseudo-pregnancy regime, provides pain relief to approximately 80% of patients (Isaacson, 1995). Another form of hormone therapy treatment involves the use of Danazol. This treatment option is often referred to as pseudo-menopause because it simulates the very low levels of estrogen that characterise menopause (Weinstein, 1992). More than 90% of women experience symptomatic relief while on Danazol. However, the use of this type of hormone therapy is frequently accompanied by unpleasant side effects such as weight gain, acne, hot flushes, muscle cramps, libido changes and fatigue. For patients who continue to experience pain despite these treatments the latest recommendation involves the administration of a Gonadotropin-releasing hormone (GnRH) agonist (Isaacson, 1995). These treatments are administered by subcutaneous injection or nasal spray for up to six months, and reduce the levels of ovarian hormones to the same levels found in women who have undergone surgical

menopause (approximately two to four times lower than achieved by Danazol). This treatment seems to provide temporary remission for most women. The side effects include hot flushes, headaches, mild depression, weight gain, decreased libido and decreased bone mass (Isaacson, 1995; Weinstein, 1992). Menstruation and ovulation resume promptly when the drug is discontinued and the GnRH analogue drugs seem to have fewer long-term side effects than the long-term use of Danazol.

Surgical intervention is divided into three categories, known as conservative, hysterectomy and definitive. Conservative surgery usually involves laparoscopy and laparotomy procedures where lesions, implants, cysts and adhesions are removed. In hysterectomy operations the uterus and cervix are removed, but at least part of one ovary is retained to maintain continued production of necessary hormones. Definitive surgery involves the removal of the uterus, cervix, both ovaries and fallopian tubes. The immediate goal of surgery is to remove as much endometrial tissue and adhesions as possible (Isaacson, 1995; Weinstein, 1992), thereby providing relief from pelvic pain. Recurrence of endometriosis following conservative surgery is common. Conservative therapy is often more successful when paired with hormonal therapy such as GnRH analogue drugs or Danazol. Hysterectomy and definitive surgery are normally only considered when vital organs are at risk, when a woman suffers such severe symptoms that she has no quality of life or when a woman has completed her family and is older. It is important for women to understand the consequences and emotional repercussions of choosing definitive surgery or a hysterectomy as treatment options. While some women feel that this choice gives them back control over their lives, others feel that the risks are too great and prefer to continue with the conservative surgical and medical interventions.

The treatment process can be extremely taxing for the sufferers. Adrien, an endometriosis sufferer, states:

I can't go on this way. I feel suspended in pain for one or two weeks each month, always having to make changes in plans. I find I don't live in the present very much. I worry about the future and how little control I have over it. I can function when I feel well, but then the disease comes back. I have to deal with the issues all over again, just when I thought I was finally beyond it (Weinstein, 1992, p. 156).



It is important that all patients understand the limitations of medical therapy. Endometriosis sufferers frequently complain that doctors fail to provide them with sufficient information (Cox, et al., 2003; Kennedy & Parkes, 2000).

### **Sexual Dysfunction and its impact on Relational Interactions**

Gynaecological patients often experience considerable amounts of distress as a result of anticipating and receiving treatments that can directly alter sexuality (Andersen, 1984). These concerns centre around the physical change due to treatment, sexual psychogenic factors and the interaction between these variables (Andersen, 1984). In order to overcome these concerns the medical fraternity needs to recognise these factors and patients need to be prepared for the changes that occur due to surgery and various medical or hormonal treatments used to combat the symptoms of endometriosis (Graziottin & Leiblum, 2005; Strzempko Butt & Chesla, 2007). The severity of these symptoms is summed up by psychologist Wanda Wigfall-Williams (cited in Weinstein, 1992, p. 177) who states that: “women who are supposed to be in the prime of their sexual lives can’t enjoy the expression of their sexuality. The mere act of penetration will send them around the bend – not in delight” (p.177).

Sexual dysfunction is often rooted in a range of predisposing, precipitating and maintaining factors (Graziottin & Leiblum, 2005). Predisposing factors include the influences of biological, psychological and contextual factors that render a person susceptible to dysfunction. These include pre-existing medical conditions such as endometriosis, the women’s body/sexual self-image, relationship issues and any contextual meanings relating to sexuality (Graziottin & Leiblum, 2005). Precipitating factors are events, situations or co-morbidities that are directly linked to the development of the dysfunction. These factors include menopause or the use of Danazol or GnRH analogue drugs. Maintaining factors are factors that prolong or intensify the dysfunctional state (Graziottin & Leiblum, 2005). These factors include delayed diagnosis, inappropriate hormonal treatment or a change in feelings toward the partner (Graziottin & Leiblum, 2005).

A number of the treatment options for endometriosis cause significant changes in body image. This is often related to weight gain, body shape changes and self-

consciousness about health issues (Graziottin & Leiblum, 2005). These changes can lead to a period of grief over the loss of perceived beauty and can increase the risk of anxiety and depression. Partner dynamics can also play a large role in sexual dysfunction. Single women often experience a dilemma with regard to partner availability, while women with partners may experience poor communication and a mismatch of sexual scripts or sexual interest (Graziottin & Leiblum, 2005). Performance anxiety can also become a problem, particularly if the woman experiences pain during or after intercourse.

The stretching and pulling of endometrial implants located behind the vagina and lower uterus usually causes painful intercourse. Dyspareunia may be continuous and occur at every sexual encounter, or it may be sporadic based on certain intercourse positions or in some phases of sexual arousal (Jarzabek-Bielecka, Radomski, Pawlaczyk, Friebe, & Biedermann, 2010). A study conducted by Jarzabek-Bielecka et al. (2010) found that dyspareunia occurs in every fourth patient diagnosed with endometriosis, making it an extremely common but poorly addressed problem. Strzempko Butt and Chelsa (2007) suggest that inadequate assessment occurs because clinicians fail to perceive issues of sexual dysfunction as relevant. Clinicians also frequently have inadequate educational training in sexual health. Couples participating in Strzempko Butt and Chelsa's (2007) study indicated that issues relating to sexuality were of primary concern and that visits to the doctor were often linked to sexual concerns. However, as a result of time constraints these concerns were rarely addressed during visits to the doctor (Strzempko Butt & Chesla, 2007). Many couples report that sex becomes a chore rather than a pleasure (Ballweg, 2004). Couples feel guilty if they have sex too often, too seldom or at the wrong times. This can create emotional turmoil for both partners and open and honest communication is required. Women need to express the nature of the pain to their partners and explain its emotional and physical effects. This creates a dialogue where women can convey their fear of intercourse or intimacy, their guilt feelings or feelings of inadequacy and their fears of losing their partners to someone else. Partners must also be encouraged to verbalize their frustrations or concerns relating to emotional withdrawal, causing pain and being rejected (Johnson, 2003; Strzempko Butt & Chesla, 2007). Communication allows the couple to move forward and to find ways to resolve the sexual dysfunction or lack of intimacy. Often experimentation with various sexual

positions, additional foreplay or identifying the times when intercourse is pain-free (such as immediately after ovulation) can help the woman to find enjoyment in the sexual encounter (Johnson, 2003). It is important for women to advise their partners if they experience pain during intercourse. Attempts to conceal pain can result in unconscious withdrawal, which can be perceived as rejection and place strain on a relationship (Johnson, 2003).

### **Depression, Despair and Anxiety associated with Endometriosis**

Most sufferers report a gradual onset of pain that then progresses to constant and chronic pain. This frequently causes a state of emotional despair, depression and anxiety (Weinstein, 1992).

Depression is characterized by intense sadness, feelings of futility and worthlessness, and withdrawal from others (Sue, Sue, & Sue, 2006). Other common symptoms include appetite and weight changes, sleep disturbances and psychomotor retardation or agitation (Barlow & Durand, 2005; Graham-Jones & Duxbury, 2000; Sue, et al., 2006).

Various studies have explored the relationship between depression and chronic illness, although there are relatively few studies that relate specifically to endometriosis and depression or other mood disorders. Studies have investigated whether individuals suffering from chronic illnesses such as endometriosis are more depressed than their healthy counterparts. A 1979 study (cited in Sepulcri & Amaral, 2009) observed a high prevalence of depression and anxiety amongst endometriosis sufferers. Simon (cited in Sepulcri & Amaral, 2009) reported a relationship between psychiatric disorders and higher numbers and severity of physical symptoms. These studies have established a firm link between chronic pain (such as that associated with endometriosis) and psychological conditions such as depression. It therefore seems likely that if endometriosis causes chronic pain, which leads to depression, this would also result in further physical symptoms. This reciprocal relationship between disease and physical symptoms has also been investigated. Studies by Waller (cited in Sepulcri & Amaral, 2009) and Lorencatto, Petta, Navarro, Bahamondes and Matos (cited in Sepulcri & Amaral, 2009) also found a link between endometriosis, anxiety

and depression. However, very few studies have investigated whether the interval between the onset of disease and the diagnosis of illness is relevant to the severity or nature of the psychological symptoms.

A study conducted by Low et al. (1993) found high rates of psychological distress and psychiatric morbidity in women attending gynaecological clinics for chronic pelvic pain. However, this study found only mild levels of depression. This result differs from that of a survey conducted by the National Endometriosis Society in the United Kingdom (Low, et al., 1993), which found that 63% of endometriosis sufferers experience depression. Low et al.'s (1993) study also found that women with endometriosis tend to be introverts with high scores on measures of psychotism and state and trait anxiety (Low, et al., 1993). Kistner (cited in Low, et al., 1993) describes women who suffer from endometriosis as over anxious perfectionists. However, it is possible that this anxiety stems from the greater risk of infertility and the uncertainty of the prognosis. This raises questions regarding whether anxiety is a vulnerability factor that makes women more prone to endometriosis, or whether anxiety is a result of endometriosis.

In a study investigating the relationship between depression and chronic illness in adolescents Key, Brown, Marsh, Spratt and Recknor (2001) found that adolescents with chronic illness have nearly twice the prevalence of moderate to severe depressive symptoms than the normal population. The specific illness had an effect on the frequency of the depressive symptoms. Adolescents who perceived their illness as mild displayed fewer depressive symptoms than those who perceived their illness as moderate or severe. However, the self-reported severity of illness did not correlate to the health care providers' rating of the severity of the illness. The findings suggest that adolescents with chronic illness are more likely than their peers to internalise their disorders.

In a study investigating the relationship between depression and quality of life in patients with multiple sclerosis, Wang, Reimer, Metz and Patten (2000) found that depressed individuals tended to over-report poor social adjustment, negative life events and dissatisfaction with social roles. This may be due to the fact that depression influences psychological variables such as perceived support, self-esteem

and locus of control. Depression may have a direct impact on quality of life through reducing memory and concentration and increasing fatigue (Wang, et al., 2000).

Bergqvist and Theorell (2001) conducted a study investigating whether hormonal treatment of endometriosis improves quality of life. The results indicated that individuals who dropped out of the treatment had significantly higher anxiety-depression scores and more sleep disturbances than the women who completed the treatment. The women who completed the treatment also had an improvement in quality of life. In comparison to a normal working population the women in this study reported higher psychological demands, a high level of authority of decisions after treatment and a higher level of pressure at work (Bergqvist & Theorell, 2001). The study showed no improvement in motivation and coping with life. It was concluded that these are issues that deeply embedded in functioning and as such they need to be addressed separately.

Other studies have focused on the relationship between depression and illness progression. Felker et al. (2001) conducted a study to explore the effect of depressive symptoms in patients diagnosed with chronic obstructive pulmonary disease (COPD). In the study a significant relationship was found between COPD and depressive symptoms. Participants also reported a significant impairment in health-related quality of life (HRQoL). This study demonstrates that depressive and anxiety symptoms are prevalent in patients suffering with chronic illness.

For many women having children is an essential part of life, and infertility can thus present as a major life stressor (Kraaij, Garnefski, Schroevers, Weijmer, & Helmerhorst, 2010). Infertility treatment can be a severe stressor and research shows that many couples undergoing infertility treatment experience mood disorders, specifically depression (Kraaij, et al., 2010). Infertility treatment often comes to dominate all facets of life. However, psychological intervention has been shown to reduce infertility-related distress (Kraaij, et al., 2010). Emotional problems are frequently exacerbated by the use of negative cognitive coping strategies such as catastrophizing and rumination. Positive refocusing can assist in reducing emotional problems (Kraaij, et al., 2010). A study by Salmela-Aro and Suikkari (cited in Kraaij, et al., 2010) showed that goal disengagement and goal re-engagement are associated

with high subjective well-being. The study found that people who were not able to adjust and disengage from their child-related goal after a negative treatment result experienced a greater increase in depressive symptoms (Kraaij, et al., 2010).

The exact nature of depression in endometriosis and chronic illness is not clear. Mood and depression may form part of the etiology of endometriosis, they may be a factor in the outcome of endometriosis or they may play a part in the presentation of the disease. Other factors such as perceived support, quality of life and roles might also influence the relationship between endometriosis, mood and depression.

### **Living with Endometriosis**

Women's emotional response to endometriosis and its treatment is influenced by various factors (Lemaire, 2004). The amount of uncertainty relates to the individual's perception of the degree of ambiguity, inconsistency and unpredictability associated with illness and illness-related events. Unclear prognosis, lack of information and unpredictable symptoms result in uncertainty, which may lead to emotional distress and relationship or adjustment difficulties. Increased uncertainty can reduce a woman's perceived sense of control, lessen her resourcefulness and hinder her ability to handle the adverse situations associated with illness.

### **Adjusting to life with Endometriosis**

People seek information when they feel that there is a gap in their knowledge that prevents them from making sense of a situation (Dervin, 1992, cited in Baker, 1996). A process of adjustment occurs when an individual is diagnosed with a chronic illness such as endometriosis. The process helps the woman to achieve meaning and quality of life in spite of the disease. These women need to re-establish their identities, renew their self-esteem and search for new meaning (Viviers, 2005). Patients need to constantly adjust to the unpredictability and degenerative nature of endometriosis.

The search for meaning often involves a need to understand the reasons why the disease has occurred and a need to understand the impact of the disease. This often results in women trying to understand, predict and control their environments. These

women feel a need to explore the implications and life consequences of a diagnosis of endometriosis.

### **Coping Strategies**

Women use various coping strategies in order to handle the stress associated with chronic disease and chronic pain. Coping refers to the way in which people deal with stressful situations and involves their attempts to manage perceived threats (Eriksen, et al., 2007). According to Baker (1996) the nature of their coping strategies divides individuals into two categories: monitors and blunterners. Monitors are individuals who cope by actively seeking information, while blunterners reject information and cope by distancing themselves from the stress-provoking situation.

According to Miller, Leinbach and Brody (cited in Baker, 1996), individuals respond to stress in a habitual manner and employ either a blunting or a monitoring style. In studies involving patients with a chronic disease it was found that information seeking began at the onset of symptoms and continued until diagnosis (Baker, 1996). In the post-diagnostic period people tend to seek practical information that can assist them in living with their condition. For most patients, the initial information source was almost always the physician and other patients. However, Baker (1996) found that the information provided by the physician was often perceived to be inadequate.

Coping strategies such as avoidance, denial, escape and self-blame contribute to psychological distress in patients. The use of approach-orientated and active coping strategies such as positive re-interpretation helps to reduce the psychological distress experienced by chronic pain sufferers (Kraaij, et al., 2010).

### **Information Seeking and Quality of Life**

A study conducted by Griffin McCook, Reame and Thatcher (2005) investigating quality of life issues in women with polycystic ovary syndrome found that the greatest concern raised by participants was body dissatisfaction, particularly weight gain and its effect on their health. This study also noted that infertility was of particular concern to the participants and was usually connected to sadness, worry about not

having children and loss of control. During the investigation Griffin McCook et al. (2005) found that many of their participants were obtaining support from available resources on the Internet, such as blogs, support groups and information sites. These resources provide sufferers with education and emotional support on a variety of topics relating to their disease.

Information exchange and emotional support are often intertwined (Velnot, 2009). Sharing health information can help build relationships between ill people and their caregivers. Network-mediated information exchange provides additional support (Velnot, 2009).

Baker (1996) found that patients with Multiple Sclerosis (MS), another chronic disease, sought information on their condition from health care professionals, family and friends and popular literature or medical textbooks. Baker (1996) also found that patients often perceive the information provided by their physicians to be inadequate and instead turn to other specialists, other patients with the disease, pamphlets, books and the media for additional information. In fact, 60% of the participants in the study indicated a need for more information. Baker (1996) also found that in order to satisfy a woman's need for information it is important that her general orientation to information be considered.

Lemaire's (2004) study also found that access to information can help to reduce uncertainty and that health care providers often lack sufficient knowledge, which leads to an increase in uncertainty. The study examined the frequency of symptoms and the extent to which endometriosis affected the lives of women with the disease. The study found that women's emotional response to endometriosis is influenced by various factors, but that uncertainty and unpredictability play a major role (Lemaire, 2004). Uncertainty has been found to decrease quality of life (Braden, as cited in Lemaire, 2004). The participants in Lemaire's (2004) study reported high levels of distress from menstrual cramps, fatigue and pelvic pain and experienced high levels of uncertainty surrounding the changing course of their disease. This study showed a positive correlation between uncertainty and distress (Braden, as cited in Lemaire, 2004).



Endometriosis and the related chronic pain also have a high economic cost that can impact on a sufferer's quality of life. A 2006 study of endometriosis sufferers (Knight, 2006) found that 17% of participants were unable to work at all due to the severity of their symptoms. The study also found that 82% of the participants had lost time from work over the past five years due to endometriosis. This is an average of 5.3 days per woman per month (Knight, 2006). Endometriosis thus adversely affects women's ability to be productive due to lost workdays (Cox, et al., 2003), this can prove very costly for an organisation. Knight's (2006) study found that women with sympathetic, supportive employers were more likely to remain in their work positions. However, due to the sensitive nature of the disease many women do not feel comfortable disclosing their condition within the workplace. Knight (2006) found that women who experience pain around their menstruation are more likely to retain their job than those who experience pain sporadically throughout the month. It often seems that endometriosis and work are a contradiction in terms. However, a number of factors determine the degree to which endometriosis impacts on a woman's ability to work. These factors include the range of symptoms experienced, whether the woman is receiving hormonal or pain treatment that is effective, the presence of a supportive network and the nature of the working environment.

### **Physician-Patient Conflict and Information Gathering**

According to Whelan (2007) physician-patient conflict concerning symptoms (patient experience) and signs (medical observations) is particularly important in endometriosis. Pain is always a subjective experience and physicians sometimes doubt the reality of the patient's experience, leading to misdiagnosis or labelling of women as hysterical or hypochondriacal (Whelan, 2007). Endometriosis is surrounded by delayed diagnosis, under-funded research, medical ignorance and medical minimalization. These factors often force women to seek support and information outside of the medical sphere. Although these factors make endometriosis sufferers vulnerable they also empower them to challenge medical authorities.

In a finding similar to that of the Griffin McCook et al. (2005) study, Whelan (2007) found that many women turn to the internet and interact with support groups and self-help organisations. These interactions form what Nelson (cited in Whelan, 2007, p.

959) refers to as an “epistemological community”. Epistemological communities share a body of knowledge and a set of standards and practices for developing and evaluating knowledge. The collective knowledge within this community is often used to critique or challenge science while promoting ongoing medical research (Whelan, 2007). In many cases women obtain basic initial information (such as a diagnosis) from their physicians and then make use of additional sources for further in-depth information. This knowledge is then used to negotiate with stakeholders, to cope with symptoms and side effects and to reduce the feelings of isolation and abnormality (Whelan, 2007).

Skuladottir and Halldorsdottir’s (2008) Norwegian study investigated the sense of control experienced by women with chronic pain in relation to their encounters with health professionals. The research focused on investigating the way in which women retain a sense of control, a positive self-image and live a normal life in spite of pain and demoralization. Skuladottir and Halldorsdottir’s (2008) study found that health professionals are seen as potentially powerful and greatly influence the experience of demoralization for chronic pain patients. Johannson and Hamberg (cited in Skuladottir & Halldorsdottir, 2008) found that women often felt ignored, disregarded and rejected when consulting with physicians, causing them to feel a loss of control and creating feelings of threat and unpredictability. Chronic pain also has a detrimental influence of quality of life. Individuals with chronic pain experience higher pain intensity, experience more somatic symptoms, suffer from depression and have a low quality of life score (Skuladottir & Halldorsdottir, 2008). Skuladottir and Halldorsdottir (2008) found that women who were able to maintain a sense of control are better able to ward off demoralization and remain empowered.

Cox et al. (2003) found that many physicians do not take endometriosis seriously and fail to provide women with sufficient information regarding the disorder. Research (Cox et al., 2003; Denny, 2009) suggests that women normally wait for about 3.7 years from onset of symptoms before they are correctly diagnosed with endometriosis. One of the reasons for this delay is that many gynaecologists believe that pain is normal when menstruating. Nearly all the women that participated in Cox et al.’s (2003) study noted that they would like more information about endometriosis, particularly with regards to the laparoscopy procedure and issues relating to

management at home. Women also want physicians to better explain the origins of endometriosis and the risks of the various treatment options. The women in the study (Cox, et al., 2003) stated that they would prefer to receive pertinent information from their gynaecologist. However, they did appreciate receiving information from a variety of sources. Finally, the respondents (Cox, et al., 2003) indicated that they would like their physicians to adopt a more sympathetic attitude towards them. They also felt that physicians should consider and discuss the potential psychological repercussions of the treatments and diagnosis, particularly with regards to infertility.

### **Identity**

Decreased self-esteem, fatigue, diminished physical ability and anxiety over pain can lead to impaired functioning and can have social and financial consequences (Viviers, 2005; Weinstein, 1992). Sufferers may isolate themselves from society and withdraw into a world of their own. Individuals with chronic pain are often concerned about becoming a burden to their loved ones and this concern places strain on relationships (Weinstein, 1992). These disruptions resulting from a diagnosis of endometriosis require a woman to manage and restructure her identity. According to Charmaz (cited in Viviers, 2005) individuals strive to achieve different identities during specific phases of their illness. Although there are difficulties most women are able to create, adapt and reinvent their lives in order to maintain a positive identity.

Beliefs about the illness are related to identity (O'Donnell, 2010). Women who are permanently symptomatic often view themselves as being permanently 'ill', while other sufferers are able to alter their illness beliefs over time. Illness beliefs are important as they affect coping strategies. A study investigating people with chronic fatigue syndrome (Moss-Morris cited in O'Donnell, 2010) found that individuals with a strong illness identity (those individuals who identified with the core symptoms of chronic fatigue syndrome) used coping strategies such as venting and excessive alcohol use and engaged in wishful thinking (O'Donnell, 2010). These individuals had lower levels of psychological adjustment. Individuals with an internal locus of control used coping strategies such as planning, active coping and positive reinterpretation (trying to look at the disease in a positive light). These participants were better

adjusted psychologically and sought emotional support for their illness (O'Donnell, 2010).

### **Guilt**

Endometriosis sufferers frequently struggle with feelings of guilt. These feelings can relate to the inability to have children or to a sense that they have let themselves, their partners or their employers down (Knight, 2006). Women often feel that they may have 'given' themselves endometriosis and experience self-blame and a sense of helplessness. In some cases, women personalise the disease and see it as a moral judgement for something they have done in the past (Medical articles, 2010), such as an abortion.

### **Self-Esteem**

According to Jones, Jenkinson, and Kennedy (2004, p. 125) many endometriosis sufferers describe themselves as feeling unwell and express concern over the reasons for the pain they experience. Feeling bloated, having greasy or spotty skin and weight gain all have a negative impact on individuals' perceptions of their physical appearance (Jones, et al., 2004). The study by Jones et al. (2003) found that many women also experience difficulty with mobility and battle to walk, stand, sit or exercise. These women also experienced sleep disturbances and changes in eating patterns (Jones, et al., 2004). During periods of pain most of the women in the sample were unable to continue with their daily activities, such as cooking and household chores, and they frequently experienced fatigue and tiredness (Jones, et al., 2004). These experiences all contribute to feelings of embarrassment and inadequacy. These experiences have a negative impact on self-image and self-esteem and leave women feeling helpless and frustrated at the lack of control over their own bodies.

Griffin McCook et al. (2005) found that weight gain is the biggest concern for women undergoing treatment for gynaecological conditions. The study indicated that body dissatisfaction due to weight gain leads to decreased quality of life. The increase in weight due to treatment, surgery or altered lifestyle leads to body dissatisfaction and lowered self-esteem and confidence. This in turn leads to social isolation and

despondency (Griffin McCook, et al., 2005). Griffin McCook et al. (2005) found that a team approach by health care workers can assist individuals in overcoming these issues by addressing nutrition and exercise along with providing emotional support for the management of gynaecological conditions.

Whelan's (2007) research found that women suffering from endometriosis have difficulty conceptualising their bodies. At times the body is conceptualised as equivalent to the self, and the women present with comments such as 'I'm sick'. At other times the body is depicted as alien to the self and the women depict the disease as something separate from them that is a burden from which they must recover. Endometriosis thus confuses the relationship between mind and self. Women often begin to doubt their own mental ability, particularly when doctors and society-at-large de-legitimize their suffering.

### **The Perspective of the Partner**

Endometriosis has an effect on the partners and family members of sufferers. Abbey, Andrews and Halman's (1991) research found that partners of women with endometriosis experience more home life stress, lower home life performance, more interpersonal conflict and less perceived control over their situation. In comparison, the women with endometriosis experience more stress, engage in more problem and emotion-focused coping and feel more responsible and more in control (Abbey, et al., 1991). However, the women find less meaning in the situation than their partners (Abbey, et al., 1991).

Fernandez et al. (2006) conducted a study focusing on the perspective of male partners and found that they often experience strong emotions including low mood, anxiety and powerlessness. Intimate partners experience adverse reactions to the onset of the disease. Following the diagnosis of endometriosis family members may react with shock, disbelief, anxiety, denial or helplessness. They may also experience anger (directed at either the patient or medical community) because the condition was not discovered sooner. The male partners reported that they found their partner's emotional need to be the most difficult to cope with and they experienced the women's emotional reactions as excessive (Fernandez, et al., 2006). Chronic illness

brings with it a change in interactions and there is an inverse relationship between catastrophizing and perceived spousal support, particularly for patients experiencing long lasting pain. Changes occur in the relationship around physical activities, such as work and household tasks, and with regards to intimacy and sexual activity (Fernandez, et al., 2006). Fernandez et al. (2006) found that male partners undergo a grieving process when coming to terms with endometriosis and this process is somewhat chaotic and iterative. The main themes for the male partners were anger, shock and denial, isolation and powerlessness, low mood, acceptance and relationship growth (Fernandez, et al., 2006). The study found that the experience of chronic illness serves to improve some aspects of relationships for couples. Couples spoke about facing the challenges of endometriosis together and the male partners commented on their partner's resilience and ability to embrace life (Fernandez, et al., 2006). An important distinction exists between men who support rather than care for their partner. Men who support their partners see them as independent, strong and courageous women. Men who care for their partners see them as dependent, weak and in need of a carer. The study also found that male partners feel that health care services should be extended to partners in order to offer them much needed support (Fernandez, et al., 2006).

### **Conclusion**

This chapter explored the nature of endometriosis. Endometriosis (and other chronic illnesses) are influenced by various factors such as severity and nature of the disease and the individual's perception of her disease. Individual disease perception seems to be a function of individual factors such as self-esteem, locus of control, social support and dissatisfaction with social roles. The nature of endometriosis forces the sufferer to continuously adjust to the demands of the disease.

The themes identified from the literature related to sexual dysfunction and its effect on relational interactions, depression, despair and anxiety. The adjustment process involves a search for meaning and dealing with guilt and issues of self-esteem. In order to cope individuals use various coping strategies, with a particular focus on information gathering. The chapter also discussed the physician-patient relationship and focused on the conflict that often exists in this relationship.

This chapter also described the impact of endometriosis on the partners of the women living with the disease. The partners experience emotional turmoil, anger, shock and disbelief and often have to provide support while attempting to make sense of their own reactions. Like their female partners these male partners undergo a grief-like process in order to achieve acceptance. This section was included because partners contribute greatly to the patient's living context and affect her experience of endometriosis.

The literature makes it clear that there is a great need for a more integrated model of endometriosis and that more education is required. Most evident is the need for the medical community to allow the emotional experiences of patients to be included in the treatment and to acknowledge and address the psychological aspects of endometriosis. This can be achieved by treating women holistically rather than only addressing the symptoms as they arise.

The next chapter presents the theoretical and methodological approach used in this study, focusing on the chosen research paradigm.

## Chapter 3

### THEORETICAL FRAMEWORK AND METHODOLOGY

#### Introduction

This chapter includes the theoretical framework and research inquiry for the study. A brief explanation of post modernism grounds the discussion of the development of social constructionism, “which specifies the nature of the relationship between the researcher and the study” (Henning, 2005, p. 68). The relevance of social constructionism is explained. The focus then shifts to the research methodology used in this study and an explanation of the research paradigm is provided. Thereafter, the research design and the role of the researcher are outlined. Finally, descriptions of the sampling technique, data collection and the data analysis process are provided and discussed.

#### Postmodernism

*Language is a labyrinth of paths. You approach from one side and you know your way about; you approach the same place from another side and no longer know your way about.*

(Arrington & Glock, 1991, p. 88)

In the twentieth and early twenty-first centuries scientific thinking has predominantly been informed by modernism. Modernism relies on logical reasoning, demonstrating confidence in science and technology. It is optimistic about the future, believes in progress and embraces humanistic values (De Vos, Schulze, & Patel, 2005). Haosheng (2004) states that modernism accepts empiricism and emphasizes observation and experimentation in psychological investigations. Modernism aims to discover generalisable laws to explain and predict human behaviour.

Postmodernism is viewed as a rejection of modernism and is a reaction against the certainty, methods and practices of modernism (Becvar & Becvar, 2006).

Postmodernism suggests that all knowledge is subjective and that no one singular



'truth' exists. Rather, it suggests that we inhabit a multiverse that is constructed through acts of observation. Postmodernists question the science's ability to generate truth because of its dependence on language, which is socially constructed and therefore distorts reality (De Vos, et al., 2005). Reality is thus seen as subjective, with facts being replaced by perspectives (Becvar & Becvar, 2006). This challenges the traditional hierarchy of knowledge in which possessors of knowledge hold the power and privilege. This subjective perspective allows postmodernists to view clients as having equally valid perspectives. Postmodernism brings into question the ownership of power and knowledge and focuses attention on discourse and role of language.

Language is built on the assumptions and world-views of social groups and influenced by the culture in which it develops (De Vos, et al., 2005). This means that language can never fully capture or represent reality. Within the discipline of psychology postmodernists are primarily concerned with the stories people tell of their experiences within their contexts of living. Facts are deconstructed by defining the assumptions, values and ideologies on which they are based. Becvar and Becvar (2006) note that postmodernists consider themselves and their own constructions in relation to life and view life with scepticism and humour. A person can only ever know what he/she constructs of others and the world (Becvar & Becvar, 2006).

In the postmodern world the self is not an isolated, autonomous being but is created through relationships (Becvar & Becvar, 2006). According to Gergen (as cited in Becvar & Becvar, 2006, p.291) "the individual is viewed as a participant in multiple relationships, with 'the problem' only a problem because of the way it is constructed in certain of these relations."

The social constructionist epistemology forms part of the broader philosophy of postmodernism.

### **Social Constructionism**

Social constructionism is a postmodern approach "concerned with explicating the process by which people come to describe, explain or account for the world (including themselves) in which they live" (Gergen, 1985, p.266). Social constructionists are

critical and progressive. They wish to show how understandings and experiences are derived from larger discourses.

The social constructionist view supports the idea of relativism. Relativism refers to the ability to perceive the world from more than one frame of reference or paradigm (De Vos, 2005). In this worldview there are many truths. However, social constructionism does not understand different views abstractly, instead it understands these views through a dimension of commitment to a standard of ethical and capable practice. Relativism renders all texts morally equivalent, but our interpretations of the text also become equally valid (Terre Blanche, Kelly, & Durrheim, 2006). Thus, social constructionism makes use of the postmodernism perspective that suggests the existence of multiple realities that are subjectively constructed through language, within a cultural and social context.

Social constructionists caution against singular accounts and the use of knowledge as power. Rather than relying on expert knowledge people are encouraged to tell their stories of lived experiences.

### **The Basic Tenets of Social Constructionism**

- The idea of a single reality is replaced with the view that multiple realities exist, since reality is subjectively constructed through the act of observation (Becvar & Becvar, 2006).
- Social constructionists adopt a critical stance toward taken-for-granted knowledge (Gergen, 1985). The power and privilege previously attributed to the possessors of knowledge is challenged.
- The process of understanding is a result of an active, cooperative endeavour between people in a relationship (Gergen, 1985). Knowledge is understood through the use of language and the meaning that it creates. Language is based on the assumptions of the social and cultural group in which it is established (De Vos, et al., 2005).
- Knowledge and social action are intertwined (Gergen, 1985). Descriptions and explanations form integral parts of various social patterns and serve to sustain, support or invite certain actions (Gergen, 1985).

These basic tenets point to several similarities between social constructionism and postmodern thinking. Firstly, social constructionism recognizes the existence of multiple realities similar to the postmodern idea of the multiverse. Secondly, social constructionism is critical of taken-for-granted knowledge. This matches the postmodern view that there is no singular truth and that alternate perspectives should be embraced. Lastly, both social constructionism and postmodernism focus on discourse and the role of language.

### **Knowledge and Power**

The medical fraternity is governed by the principles of modernism, where the professional holds the power and control in the patient-professional relationship. In the modernist world doctors approach endometriosis from a first-order cybernetic perspective, attempting to describe what is going on inside the system from a position outside the system.

Social constructionism brings additional awareness and challenges the established hierarchy. This takes the form of a challenge to the power of so-called experts and their privileged information (Becvar & Becvar, 2006). Social constructionism suggests that all people have the right to develop their own expertise relative to their own lives. In this study the participants are the experts on the effects of endometriosis on their lives, while the doctors are the experts on the management of the disease. In this way the participants and the doctors co-create a shared reality. Treatment of endometriosis should be a dialogue between all stakeholders with the goal of creating a context in which the participants' needs and desires are facilitated.

Social constructionism recognises the role that individuals play in creating and maintaining the narratives or institutions of power. Individuals may in fact have created that which they find oppressing (Henning, 2005). Social constructionism removes knowledge from the data-driven or objective domains and gives it to individuals within a relationship (Gergen, 1985). This knowledge then becomes the responsibility of people through active and communal interchange (Gergen, 1985). Perspectives replace facts, and reality is constructed through observation. In social constructionism clients possess equally valid perspectives and, according to Gergen

(as cited in Becvar & Becvar, 2006, p. 91) “we must become aware that there is no ‘transcendent criterion of the correct’.”

In the present study, the researcher explored the ways in which participants experience endometriosis and the effects of endometriosis on the lives of the participants. This research question brings into question the ownership of expert knowledge. The researcher is of the belief that the knowledge in this study was created within the relationship between the participants, the professionals and the researcher. The participants made use of language to communicate their knowledge. The concept of language is explored further in the following section.

### **Language**

Language is a crucial component of the postmodern world. “Language helps to construct reality” (Terre Blanche, Kelly, et al., 2006). Social constructionism is concerned with the broader patterns of social meaning encoded in language. Language limits what we are able to experience and perceive, because the language available is influenced by the individual’s social and cultural context. Thus, individuals come to know their world through language, yet through their knowing they simultaneously construct their world (Becvar & Becvar, 2006).

Social constructionist research aims to deconstruct facts and to describe the assumptions, values and ideologies on which these facts are based. Social constructionists also consider their own constructions when conducting research.

In social constructionist thought the self is not recognised as an isolated, autonomous being, but is constructed in relationships (Becvar & Becvar, 2006). In the same way truth or reality can only be evaluated within a perspective, as it does not necessarily represent the real world. Language is thus a shared activity that is essential in the negotiation of understanding. The study of knowledge becomes the study of the active use of language in human behaviour (Gergen, 1985).

An individual’s social and cultural background constructs the meaning of words and actions. Language thus describes a culture of meaning and the understanding of

specific words is agreed within that culture (Henning, 2005). However, this culture construction cannot fully describe the meaning that is created through individual experience, since personal experience is distinctive. Therefore, the context of the lived experience is integral to understanding reality. Meaning is not generated in single words but by words in relation to context, and no two contexts are ever the same. The meanings of words are thus infinite and are negotiated by people in dialogue (Terre Blanche, Kelly, et al., 2006).

Being open to communication with others exposes us to others' experiences. Through these conversations alternative meanings can be discovered, which can then alter our understandings of our own meanings, creating a shift in our reality. This highlights the idea that reality is co-created (Becvar & Becvar, 2006; Gergen, 1985).

The origins of social constructionism are often traced back to Ferdinand de Saussure, a linguist who introduced a fundamental distinction between *langue* (the system of language) and *parole* (its use in actual situations). We use language (*parole*) to mean something in particular, however we are constrained in what we say by the limited possible meanings made available to us by language (*langue*) (Terre Blanche, Kelly, et al., 2006).

A conversation between Alice and Humpty Dumpty in Lewis Carrolls' *Through the Looking Glass* (Carroll, 1896/2004, p. 184) demonstrates the constraints of language.

"I don't know what you mean by 'glory'," Alice said.

Humpty Dumpty smiled contemptuously. "Of course you don't – till I tell you. I meant 'there's a nice knock-down argument for you!'"

"But 'glory' doesn't mean a 'nice knock-down argument'," Alice objected.

"When I use a word," Humpty Dumpty said, in rather a scornful tone, "it means just what I choose it to mean – neither more nor less."

"The question is," said Alice, "whether you can make words mean so many different things."

"The question is," said Humpty Dumpty, "which is to be the master – that's all."

Alice was too much puzzled to say anything; so after a minute Humpty Dumpty began again. “They’ve a temper some of them – particularly verbs: they’re the proudest adjectives you can do anything with, but not verbs – however, I can manage the whole lot of them! Impenetrability! That’s what I say!” (p. 184).

Saussure (Terre Blanche, Kelly, et al., 2006) states that language is a system of meanings and not a collection of signs pointing to a particular concept. As a system of meanings and practices language constructs reality. The social world is therefore interpreted as a kind of language. Language is how we express our experiences and create meaning from them. It is through language that we are able to tell our stories and make sense of our world (Terre Blanche, Kelly, et al., 2006).

In this study, sufferers of endometriosis were given the opportunity to tell their stories about their experiences within their contexts. In the modernist perspective the medical professionals possess the expert knowledge and the power in the endometriosis relationship. This study aimed to reposition the power by acknowledging the valid experience of the participants and allowing them to be the experts in their own lives.

We all have the freedom to choose our attitude in a given circumstance, but this belief may appear naïve to women who have lost their ability to have children, or who suffer chronic, debilitating pain. It is only through hindsight and deep reflection that these women may be able to reconstruct and derive meaning from their experiences. Social constructionism provides an adequate point of departure for this study as it provides a platform to acknowledge and deconstruct the women’s experiences of pain and hurt.

### **Within the Present Study**

Exploring the psychological effects of endometriosis from a social constructionist perspective challenges dominance of the empirical discipline of medicine. In this study, the participants share their stories of their experiences of living with endometriosis. In telling their stories to the researcher, meaning was co-created through the dialogue between researcher and participant. The researcher aimed to understand the participants’ world from their own perspective, taking into

consideration the context and cultural influences. In sharing their stories with the researcher, the participants were able to reflect on the meaning of their experience and possibly co-create new meanings. In keeping with the social constructionist paradigm the researcher's stance was not objective but instead was influenced by the research and exerted an influence over the research.

## **Inquiry**

### **Overview of Qualitative Research**

Qualitative research is naturalistic, holistic and inductive (Durrheim, 2006). It studies phenomena as they take place in the real world. Phenomena are thus viewed within the social context in which they occur. It is possible that the same experience will have different meanings in different contexts; this supports the theory of multiple realities. Qualitative research is informed by an inductive approach that involves immersion in the data in order to discover categories, dimensions and interrelationships. Instead of testing theoretical hypotheses the qualitative inductive approach involves exploring the phenomena through genuinely open questions (Durrheim, 2006).

According to Cresswell (2007), qualitative research is an inquiry process of understanding that explores a social or human problem by making use of distinct methodological traditions. Qualitative research focuses on the meanings of lived experiences and involves observation and data collection in natural settings. Qualitative research was therefore deemed appropriate for the purposes of this research project, as a descriptive and contextual approach was required in order to facilitate a rich exploration of the experiences and core psychological effects of endometriosis on participants.

In the present study participants' experiences and emotions were not reduced to statistical equations. Instead, the researcher aimed to understand the participants' accounts of meanings, experiences or perceptions relating to endometriosis (Fouche & Delpont, 2005). In order to attain this knowledge the researcher made use of a flexible problem formulation strategy that developed over the course of the investigation.

The qualitative paradigm facilitated an element of interaction between the researcher and the participants that was appropriate given the researcher's personal interest in the topic. This interaction allowed the researcher and the participants to co-create the meaning of the phenomena. The researcher was thus able to gain a first-hand, holistic and insightful understanding of the ways in which the participants perceive, understand and explain their world. This enabled the researcher to identify the perceptions and beliefs that underlie the phenomenon of endometriosis. Qualitative research involves gaining a personal knowledge of the participants' hopes, fears and struggles.

The purpose of the present study was not to seek objective scientific truth, but rather to create a better understanding of the lived experience and meaning underlying endometriosis. The use of a qualitative and social constructionist approach allowed the researcher to add value to the meaning attributed to each situation by considering each individual's background and experience of endometriosis. The choice of the qualitative paradigm allowed for the possibility of multiple realities. In this way the social contexts in which meaning is created were acknowledged and the researcher's subjectivity and relationship with the participants were embraced (Viviers, 2005).

### **Design of Inquiry**

This research made use of a non-experimental, qualitative format where individual interviews were used to gather data. Non-experimental research is defined as research that does not involve an experiment (McBurney, 1990) and is often also referred to as correlational research. This type of research seeks to establish correlations between variables. The aim of this research study was to examine the relationship between psychological effects and endometriosis.

Relationships should never be examined in isolation. The context or setting in which a problem occurs is of utmost importance. This context may include the family system and cultural, historical and political background. In this research study it was not possible to conclusively determine which variable served as the cause. Instead, the researcher felt that it was important that the research provide a complex, detailed understanding of experiences of endometriosis. It was also considered important that



the participants were empowered to share their stories and speak for themselves, without the researcher imposing any positivistic expectations of the themes that would arise.

Non-experimental research, such as the research conducted in this project, can start to answer theoretical questions and lay the groundwork for further experimental research in the field (McBurney, 1990).

### **Sampling**

The specialised nature of the topic led to the use of purposive sampling (Strydom, 2005). This type of sampling ensures that the participants are all eligible for inclusion in the study (McBurney, 1990). Purposive sampling allows for the non-random selection of participants for a particular research reason. A difficulty in purposive sampling relates to the possibility of the researcher making an error in selecting the sample (McBurney, 1990). This problem was overcome through the use of an eligibility questionnaire that ensured that the participants had a confirmed diagnosis of endometriosis. The questionnaire also ensured that the participants were of legal age to participate in the research and provided the researcher with additional contextual information.

The participants represented a difficult-to access population (Breakwell, Hammond, & Fife-Schaw, 2006). The initial participants were thus asked to introduce the researcher to other potential participants (Durrheim & Painter, 2006), a technique known as snowball sampling. Snowball sampling is often used when investigating a relatively unknown phenomenon (Strydom, 2005).

Participants who were willing to talk about their personal experience of endometriosis were selected for inclusion in the study based on their confirmed diagnosis of endometriosis through laparoscopic surgery. It was important that the sample was representative of the population being studied in order to provide rich detail and maximize the range of information obtained. The aim of purposive sampling is to purposively seek typical and divergent data (Strydom & Delpont, 2005b).

The sample for this study consisted of five adult women who had all received a confirmed diagnosis of endometriosis through laparoscopic surgery conducted by a gynaecologist. More specific information on each of the participants is provided in chapter four.

### **Open-ended interview**

The data was collected by means of individual interviews with each of the participants. An open-ended interview format was chosen because the research focused on the experiential aspects of living with endometriosis and the psychological effects of this experience. The interview was semi-structured and included a series of open-ended questions and prompts where appropriate. Examples of topics covered include: How the women experience living with endometriosis; how the disease has impacted on their self-identity or self-image; how endometriosis has influenced their concept of femininity; whether they feel that there is sufficient support and availability of information from the medical community; and how they were initially exposed to the diagnosis of endometriosis. These topic areas were designed to assess the participants' perceptions, feelings and opinions with regards to the topic being researched. This was done in order to maximize the chances of collecting adequate, satisfactory and hopefully novel data (Breakwell, et al., 2006). The respondents were also able to spontaneously expand on answers (Campbell cited in Greeff, 2005; Rosenthal & Rosnow, 2008). The participants' responses were audio taped by means of a digital voice recorder and later transcribed by a professional transcriber. This allowed for the collection of a full record of the events (Greeff, 2005) and meant that the researcher was able to concentrate on the interview instead of taking notes. The transcribed notes allowed for more efficient and clear thematic content analysis. The interviews lasted an average of 35 minutes each. The participants were interviewed in the following order: Estelle, Anne, Charlene, Phillipa, Kaitlyn. The interviews with Estelle and Charlene took place in the researcher's home. Phillipa was interviewed at the home of a relative in Johannesburg, as she lives in Mpumalanga. The interviews with Anne and Kaitlyn were conducted in their homes in Johannesburg. The questions posed to the participants were largely unstructured. This gave the interviews a conversational tone. Each participant was given ample space to reflect on their experiences in a manner in which they felt comfortable.

The researcher also considered the fact that responses within the context of face-to-face individual interviews are both verbal and non-verbal, involving non-verbal communication such as body language and eye contact. It is possible that a more structured approach using forced choice questions would have provided more comparable responses (Rosenthal & Rosnow, 2008).

The research topics were formulated in accordance with the reviewed literature but included questions related to the researcher's personal experience and personal curiosity (Breakwell, et al., 2006; Creswell, 2007; Strydom & Delpont, 2005a). However, care was taken to ensure that the issues dealt with were related to the original research questions (Creswell, 2007).

### **Establishing Credibility in the Study**

The roles of validity, reliability and generalizability have been questioned within the qualitative paradigm. This is because the concepts of validity, reliability and generalizability are rooted in the positivistic perspective of quantitative research, and rely on observable, measurable facts (Golafshani, 2003). Reliability refers to the extent to which results are consistent over time, in other words reliability focuses on whether similar results can be produced under similar conditions (Golafshani, 2003). In qualitative studies a high degree of stability indicates a high level of reliability. Validity refers to the accuracy of the means of measurement and focuses on whether a measure actually measures what it intends to measure (Golafshani, 2003).

In contrast, qualitative research is a naturalistic approach that seeks to understand phenomena in a real world setting rather than in a contrived setting (Golafshani, 2003). Researchers using the qualitative paradigm seek to understand and illuminate the phenomena and do not aim to predict results or generalize findings.

Peer evaluation remains important in qualitative research but the nature and purpose of qualitative research differs from that of quantitative research and therefore the same worthiness criteria cannot be applied (Krefting, 1991). De Vos et al. (2005) emphasize the need for a different language with which to evaluate qualitative

research. It is suggested that in the evaluation of qualitative research the concepts of validity and reliability be replaced by descriptions of the study's trustworthiness, credibility, confirmability, transferability and dependability.

In quantitative research the quality of the research is evaluated with reference to its generalizability. The equivalent concept in qualitative research evaluation refers to the trustworthiness of the research. Trustworthiness refers to the truth-value of qualitative research, which relates to the degree to which a study provides an accurate representation of the participants' experiences and perceptions.

In qualitative research the concept of reliability is linked to an evaluation of the quality of the research. More specifically, reliability in qualitative research relates to the dependability of the research. Dependability is achieved through an auditing process (Tobin & Begley, 2004) that implies that variability due to personal experiences can be assigned to identified sources. Researchers are responsible for ensuring that the research process is presented in a logical, clear and traceable document. Dependability can be demonstrated through an audit trail (Tobin & Begley, 2004) that includes the researcher's documentation of data, methods, decisions and end-products. Reflexivity is also related to reliability (Tobin & Begley, 2004). Reflexivity involves researchers keeping a self-critical account of the research process. This information can then be used to authenticate confirmability. It is possible to improve the dependability of qualitative research through the use of a code-recode procedure.

In qualitative research, the concept of validity is described through a wide range of terms and is not a single, fixed or universal concept. Instead, validity in qualitative research is "rather a contingent construct, inescapably grounded in the processes and intentions of particular research methodologies and projects" (Golafshani, 2003, p. 602).

Qualitative researchers acknowledge the need for some type of evaluation of qualitative research. The validity of qualitative research may be affected by the researcher's perception of validity and his/her choice of paradigm. Consequently, validity in qualitative research has been redefined in terms such as credibility and

transferability (Golafshani, 2003; Tobin & Begley, 2004). Transferability is comparable to external validity and refers to the generalizability of the research. Transferability also involves an evaluation of whether the research contains enough descriptive data for comparison with other research. Within a naturalistic study such as this, the concept concerns only case-to-case transfer.

Credibility, which is comparable to internal validity, looks at whether the explanation fits the description and whether the description is credible (Tobin & Begley, 2004). According to Lincoln (as cited in Tobin & Begley, 2004) credibility can be achieved through member checks, peer debriefing, prolonged engagement, persistent observation and audit trails.

Triangulation is a strategy that qualitative researchers use to ensure validity (Creswell, 2007; Golafshani, 2003; Tobin & Begley, 2004). Triangulation involves the use of multiple sources, methods, investigators and theories in order to provide corroborating evidence (Creswell, 2007).

Within qualitative research reliability can be attained in the following ways:

- Disclosure of orientation involves identification of the researcher's preconceptions, values and expectations for the study and theoretical orientation. This identification then creates a milieu that places the perspectives and themes in context. For this research the researcher has disclosed that the theoretical orientation for this study was social constructionist in nature.
- The social and cultural contexts of the participants are made explicit through the stories told. It is important to provide information on the context in which the data was gathered. This helps to ground the researcher and the reader in the perspective from which the phenomena were viewed. In terms of this research it has been explained that the research was conducted in order to provide a better understanding of the psychological effect of endometriosis on women in the South African context. Although the study was conducted partly for academic purposes, the researcher felt that it was important to tell the stories of women living with endometriosis in South Africa.

- The impact of the research on the researcher is made explicit in her own personal reflections. These personal reflections could include emotional difficulties encountered by the researcher, areas of revelation and the ways in which the research has extended her understanding of endometriosis. The researcher's feelings and reflections on the subject material are included throughout this research report.
- Dependability is achieved through engagement with the material. The researcher immersed herself in the material relating to endometriosis. Initially, the researcher needed to find appropriate literature relating to the psychological effects of endometriosis. This literature then formed the basis for the interviews that were conducted. In order to gain a better understanding of the participants the researcher then immersed herself in the texts generated from the interviews. This involved reading and re-reading the transcripts and highlighting promising ideas and key passages in order to conceptualize and re-conceptualize key observations. The interpretations were then linked to direct quotations from the original texts.
- To provide additional dependability, the researcher made use of an impartial co-coder who analysed the data independently. The purpose of the co-coding was to determine whether the thematic analysis was truly representative of the data. Through a consensus discussion, both parties agreed with the final themes that are presented in this research.

In this study the researcher aimed to achieve validity in the following ways:

- Triangulation involves seeking information from multiple sources and multiple perspectives. The researcher made use of several viewpoints and ideas in order to clarify her own position. These viewpoints included a review of available literature, the conducted interviews, the themes suggested by the researcher and the co-coder and conversations with various stakeholders and peers.
- The research is coherent as it gives both the researcher and the participants a voice.
- The research attempts to meet the criteria for credibility by making use of a number of strategies including prolonged engagement, facilitative communication, peer examination, member checking and the authority of the

researcher. Prolonged engagement was achieved by providing an honest and open forum for the participants to share their stories. In order to build rapport and establish a relationship with the participants the researchers spent time with the participants before and after the interviews. After the interviews had been completed the researcher maintained contact with the participants, sending them the thematic analysis to review. The researcher also promised to give each of the participants a copy of the completed dissertation. Another technique used to enhance credibility was facilitative communication. This involved the use of probing, clarifying, summarizing, silence, minimum verbal response and reflection during the interviews.

- Transferability was enhanced through the use of purposive sampling, which ensured that the participants were able to provide the researcher with rich, detailed information.
- The use of direct quotations in the results chapter serves to remind the reader and researcher that the stories and comments depict one version of events and are not necessarily an accurate depiction of the subject's experiences. The interviews were a co-construction between the researcher and the participants.

Guba and Lincoln (1989) highlight the importance of confirmability and taking note of researcher bias. Confirmability specifies that the values, motives and biases of the researcher be acknowledged in order to ensure that the data and interpretations of the findings are not simply figments of the researcher's imagination, but are clearly derived from the data (Tobin & Begley, 2004). Within this research social constructionist thinking provided the framework for the researcher's preconceptions and opinions.

### **Ethical Considerations**

Within qualitative research ethics are closely linked to the concepts of credibility, dependability and confirmability. This research was guided by the ethical requirements of the profession of psychology as laid out in the HPCSA's (Health Professions Council of South Africa) ethical code of practice for psychologists.

The sensitive nature of the issue under investigation meant that the welfare of the participants was of supreme importance. Participants were fully informed of the purpose of the research by way of written and verbal correspondence before the actual interview was conducted. Participants also received a letter of information. The researcher obtained informed consent from all participants, both for participation and for audio recording of interviews. The expected benefits and risks of participation were also discussed with the participants.

The researcher felt that it was important to be aware of her own pre-conceived ideas regarding the topic. The researcher also took note of any potential issues that the participants might experience. Care was taken to ensure that the participants did not feel compelled to answer any questions that triggered anxieties or uncomfortable emotions pertaining to the psychological effects of endometriosis. Participants were able to withdraw from the study any time without experiencing any negative consequences. Due to the personal subject matter discussed in the interviews, only the researcher has access to the original transcripts and audiotapes, These audiotapes and transcripts have been safely stored until the research report has been accepted and will be destroyed after the report has been accepted. The participants have been made aware of this procedure. Every attempt was made to ensure the privacy and confidentiality of the subject and material. In the data analysis and written transcripts participants are referred to by first name only in order to protect their identity. Third parties that were involved, such as the transcriber and co-coder, were required to sign a confidentiality agreement in order to maintain the privacy of the participants.

Lastly, it was important that the researcher avoid ambiguity with the participants. This was achieved through clearly defining her role as the 'researcher' at the beginning of the interview process.

### **The Roles of the Researcher and the Participants**

In keeping with the qualitative research paradigm the researcher's stance towards the participants and the topic was not objective. Qualitative research holds that it is impossible to explore and understand other people's experiences without first acknowledging the influence of our own experiences. Throughout the research report



the researcher provides reflection and makes her own view known – this allows the reader to judge the biases of the researcher. The researcher also has to bracket her own views in order to ensure that they do not dominate the interpretation of the participant's stories. The researcher and the participants are all active participants in the research process, as each brings their own experiences, history, views and traditions. The relationship between the researcher and the participants also influences the research.

It is important that the purpose of the research is clearly stated before the project commences. In this study the researcher informed participants that the study related to the psychological effects of living with endometriosis. The researcher's aim was to create better understanding of endometriosis and its effects by looking at endometriosis through the eyes of those living with this disease. The participants were aware that the study would give them the opportunity to tell their stories about their lived experiences.

The researcher explained to the participants that most previous research had been done from a modernist perspective, focusing on the tangible, medical symptoms of endometriosis. The focus on this previous research was not on the individuals living with the disease. The focus of this study was therefore the personal experience of the illness and its impact on each participant. The researcher expressed the hope that in sharing their stories and reflecting on their experiences the participants' would be able to provide meaning.

At the outset of the study the researcher described her role to her participants. Her interest in endometriosis is both personal and professional. She was diagnosed with endometriosis 8 years ago and has undergone extensive surgery over the past 7 years, along with a number of other treatments for the disease. During this personal struggle with endometriosis, the researcher realised that traditional medical training emphasized the disease and not the person with the disease. This led the researcher to question where real expertise lies – whether with the medical professional or the person living with the disease. Participants were made aware of the researcher's personal and professional interests.

Prior to contact with the participants the researcher conducted an extensive literature survey on the subject of endometriosis and the psychological effects of the disease. The literature reviews showed that there is very little research worldwide focusing on these psychological aspects of endometriosis. This lack of available literature, along with other researchers' opinions on the subject of endometriosis, also contributed to the researcher's perceptions.

The target population was women who have been diagnosed with endometriosis by a gynaecologist, by means of laparoscopic surgery. Accuracy in the selection of participants was achieved through the use of inclusion and exclusion criteria covered in an eligibility questionnaire.

The researcher decided to be transparent and to disclose to the participants that she is also an endometriosis sufferer. The main advantage of disclosure is that it allowed the researcher to build a rapport with the participants and put them at ease when discussing experiences of such a personal nature. The researcher was also able to explain to the participants that privacy is of utmost importance to her as a fellow sufferer, and that she respected and understood their concerns.

Greeff (2005) recommends that researchers engage in self-examination and master interpersonal and communication skills in preparation for the interviews. In order to achieve this, the researcher bracketed her experience and tried to reduce her personal input, biases and effect during collection and analysis of data. The researcher suffers from endometriosis herself and thus might assume that her experiences are similar to those of the participants. It was important to ensure that participants fully described their experience and that she did not use her personal knowledge of the disease to fill in any gaps in the accounts. The researcher acknowledges that she has a bias against certain treatment options, as they have not been successful in her own treatment. The researcher ensured that she did not lead the participants during the interview with regards to these biases.

## Analysis

Data analysis refers to a collection of methods that extract pertinent information from the mass of data that is collected in qualitative research. According to (Creswell, 2007) the processes of data collection, data analysis and report writing are interrelated and qualitative researchers often learn by doing. The data analysis spiral best represents this process.

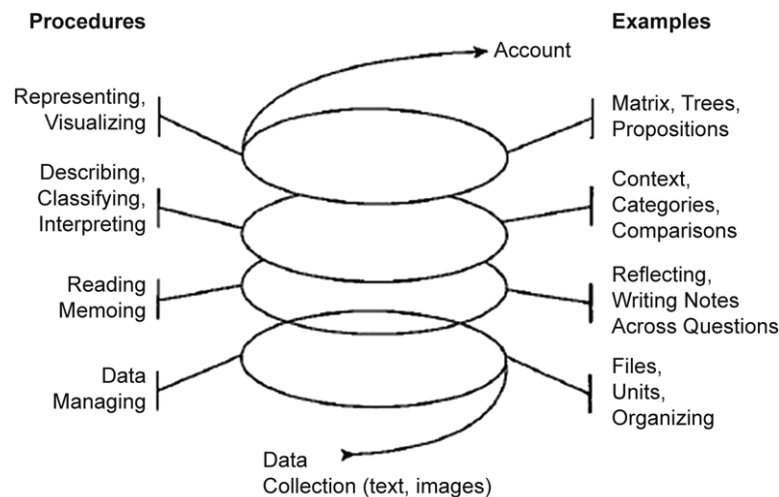


Figure 3.1. Data Analysis Spiral (Creswell, 2007 p. 151)

In this study the data analysis involved the use of thematic analysis, which is a descriptive presentation of the data achieved through identification of common themes in the analysed text (Anderson, 2007).

This data analysis strategy was aided by and presented through thematic networks, allowing the researcher to recognize and describe themes within the data and also search across the interviews in order to find repetitive patterns. The networks extracted basic, organising and global themes that were then symbolized in a web-like map portraying the relevant themes at the various levels, as well as demonstrating the relationships between each level (Attride-Stirling, 2001). Thematic analysis as a qualitative data analysis method falls within the tradition of hermeneutics.

## Hermeneutics

Hermeneutics interprets the “texts” of life (van Manen cited in Creswell, 2007, p. 59). It is a process that begins with listening and observing, and then gathers momentum

as the researcher progresses through thematising, coding and writing a final interpretive account (Terre Blanche, Durrheim, & Kelly, 2006).

Hermeneutic understanding cannot be applied from the outside, instead it assumes that the interpreter 'knows' to some extent the phenomena he/she seeks to understand (Reason & Rowan, 1981). The researcher has personal experience with endometriosis and therefore had some knowledge of the material under consideration. However, this research has provided her with a deeper understanding and new insights into the effects of endometriosis.

As a methodology, hermeneutics prescribes what is known as the 'hermeneutic circle', a method in which the interpretation of a text and the meaning of the parts should be considered in relation to the meaning of the whole. However, the whole can only be understood in respect of its constituent parts (Kelly, 2006). There is thus circular movement between the whole and the parts.

A close examination of the participants' stories shows that they consist of an assortment of various pieces. These pieces are the participants' feelings, anecdotes and isolated beliefs. However, when the material is seen from a distance the separate pieces cluster into patterns and themes. Through this distance the meaning of the whole becomes apparent.

Qualitative research looks for commonalities in material. At the same time, differences are noted and the search for differences is allocated the same priority as the search for commonalities. This search highlights what is distinctive about each individual case or context and provide a deep understanding of the research study (Kelly, 2006).

Hermeneutics was considered an appropriate data analysis strategy for this research study as the research aimed to view phenomenon of endometriosis from within the context of South African women who suffer with endometriosis. In order to be holistic, the research had to take into account various temporal, familial, social and cultural factors that play a role in the lives of women who suffer with endometriosis.

Hermeneutic analysis corresponds with the key tenets of social constructionism, in that it aims to be sensitive to the systems of knowledge and meaning to which it gains access (Lurie, 2007). Hermeneutic analysis allowed the researcher to experience a degree of independence whilst exploring the effects of endometriosis as detailed by the participants. This in turn gave the participants' stories life, while remaining aware of the context of the stories.

### **Steps towards gathering Data**

The following steps were followed in order to obtain the data to be analysed (Kelly, 2006):

- The participants were informed of the purpose of the study by means of a letter of introduction. Prior to the interview the researcher explained the purpose of the study to the participants and also informed the participants of their ethical rights in association with the study. The researcher then obtained informed consent from the participants to participate in the study and to be audio taped. The letter of information is included in Appendix A. The consent forms to participate and to be audio taped are found in Appendix B and the biographical questionnaire is included in Appendix C.
- On completion of the interviews, the digital recordings were sent to E-Transcribe, an independent transcription service, for transcription. E-Transcribe signed a confidentiality agreement and agreed to maintain the participants' privacy and right to anonymity. A sample of the transcribed interviews can be found in Appendix D.
- The researcher carefully read and re-read the transcripts in order to immerse herself in the material. This allowed the researcher to become acquainted with the data and to begin to conceptualise interpretations and meanings.
- The researcher then identified themes using a bottom-up approach. This established the organizing principles that occurred naturally within the text.
- Finally, the researcher discussed the analysis of identified themes for each participant. This was followed by a comparative analysis of the experiences of all the participants linking the themes to relevant literature.

## **Principles guiding the categorizing of data**

Interpretive data analysis rarely proceeds in an orderly manner and a plethora of techniques is available. In general, interpretive data analysis involves the following steps laid out by Terre Blanche et al. (2006, p. 322).

### **Step one: Familiarisation and Immersion**

In qualitative research data analysis is interpretive and the researcher has pre-existing ideas and theories concerning the topic under investigation. These ideas and theories exist prior to data collection. In this case, these ideas and theories related to the researcher's own knowledge and beliefs regarding endometriosis.

After collecting the data through one-on-one interviews, the researcher immersed herself in the material, working with the texts that were generated. She concentrated on the world that was depicted in the texts and attempted to make sense of the participants' experience of endometriosis. Carefully listening to the digital recordings and reviewing the texts made it possible to detect the underlying emotional tone of the text. The process of immersion embraces unpacking, which is the way we lay out the meanings of words and images (Kelly, 2006). This unpacking allowed the researcher to create lists of everything that came to mind when thinking of the texts. These lists were used to generate an overall idea of the information gathered. This information could then be assembled into larger categories and networks (Kelly, 2006).

### **Step two: Inducing Themes**

Once the researcher felt confident that she was familiar with the texts, she began the process of generating themes. This is a bottom-up process that started by determining the organising principles naturally underlie the material (Terre Blanche, Durrheim, et al., 2006).

Terre Blanche et al. (2006) suggest five steps involved in data organisation.

- 1) Use the language of the interviewees in order to label the categories, rather than using abstract theoretical language.
- 2) Move beyond summarizing content and think in terms of the processes, functions, tensions and contradictions found in the text.
- 3) Find an optimal level of complexity where there are sufficient themes to make the data interesting, without too many surplus themes that detract from the focus of the study.
- 4) Do not settle for one system too quickly.
- 5) Do not lose focus of the aim of the study and ensure that the themes relate to the aim.

### **Step three: Coding**

Coding should begin during the development of the themes. Initially, the researcher coded individual words, sentences and phrases, These were then grouped together under specific themes.

### **Step four: Elaboration**

During this stage the researcher explored the themes more closely, in order to capture any nuances that were missed during the initial stages of coding (Terre Blanche, Durrheim, et al., 2006). This allowed the researcher the opportunity to revise the coding system and drew attention to potential sub-issues or themes that were previously missed. Commonly reported arguments and ideas from the surveyed literature could now be used to complement a text that was able to speak for itself.

### **Step five: Interpretation and checking**

During this stage the researcher reviewed the interpretation of the material using thematic networks. The interpretation of the data was also compared to the original research question. Common themes were identified and substantiated through the use of quotations and excerpts from the transcribed interviews. This stage also allowed the researcher to reflect on her role in the collection and interpretation of data and to

acknowledge that her personal experience with endometriosis influenced the research process.

### **Thematic Network Analysis**

Thematic analysis was aided by and presented through thematic networks. These are web-like illustrations (networks) that summarize the main themes in a piece of text (Attride-Stirling, 2001). The networks extract basic themes (lowest-order ideas evident in the text), organising themes (basic themes grouped together to summarise more abstract principles) and global themes (groups of organising themes that present an argument). This process can be broadly divided into three stages: (a) the reduction or breakdown of the text; (b) the exploration of the text; and (c) the integration of the exploration. At each stage the researcher aims to achieve a more abstract level of analysis.

### **Conclusion**

In this chapter, qualitative research and the specific research design were discussed. The nature and complexity of endometriosis means that a better understanding of the illness and the diverse effects experienced by sufferers is needed. In order to create a rich and extended understanding of endometriosis this study gave women living with endometriosis the opportunity to tell their stories about their experiences, hardships and lives. It is through these lived experiences that a gateway for insight is created. These experiences cannot be quantified; instead they are situated within the context of the South African community and each individual's life context. The research did not aim to give explanations or theories regarding the cause of endometriosis, nor does it claim that these experiences described in this research report are the only true description of the experience of endometriosis. It is hoped that the information gained in this research will help people to understand the complexity of endometriosis and to appreciate the importance of nurturing women with this disease in a holistic manner. Such nurturance will hopefully involve an acknowledgment of the effects of endometriosis and a valuing of the individual perspectives of the sufferers.



The opportunity to interview ordinary women with extraordinary stories was a privilege and a revelation. Their narratives are discussed in the following chapter.

## Chapter 4

### THE VOICES OF ENDOMETRIOSIS

*Research is to see what everybody else has seen,  
And to think what nobody else has thought.*  
(Szent-Gyorgyi, 2010, p. 1)

#### Introduction

Endometriosis is a pervasive disease and although this study relates to the psychological effects of endometriosis, many diverse themes arose from the interviews. These themes construct the day-to-day lived experience of women with the disease and have thus have been included in the analysis. The way in which the women relate to endometriosis gives voice to their trauma, constructs their identity, interacts in their relationships and helps them makes sense of the world in which they live. This chapter explores the main themes that emerged from the texts. A sample of the transcripts (texts) is attached in Appendix D and full transcripts are available on request.

It is important to note that the themes that were identified are influenced by the researcher's personal experience with the disease. For this reason, the identified themes do not represent the only truth for these participants. Instead they simply reflect a set of possible interpretations emerging from the perspective of the researcher. The themes are also not exhaustive, as another person may have highlighted different or additional themes. The results are also not generalisable to all women living with endometriosis, but are based on unique and individual stories.

The themes highlighted in this chapter appear to be central to the experience of living with endometriosis. The participants in this study were interviewed at different stages in the progression of their disease. The participants were also at different stages in their own lives. This impacted on their diverse experiences and made each story unique.

Throughout this chapter, the researcher refers to herself in the first person. Due to the personal and intimate nature of the discussions, I felt that it was important to represent the stories authentically. As a researcher, I thus felt that the stories needed to be presented in the personal manner in which they were conducted. I aimed to achieve this through the use of a more natural dialogue created by using the first person.

The themes that were extracted from each story are organised into thematic networks on three levels: basic themes, organising themes and global themes. The interpretation discusses the organising themes, which include the basic themes, and then discusses the global themes. This presentation arrangement provides a logical format for the presentation and demonstrates the way in which the themes emerged from the data.

## **Charlene's Story**

### **Background Information**

Charlene's endometriosis experience began when she reported severe abdominal pains in 2003. The doctor's thought initially thought the pains were related to her appendix, but following an ultrasound they discovered a cyst the size of a tennis ball. When they operated to remove the cyst, the surgeon discovered and diagnosed her endometriosis. To date, Charlene has had one laparoscopic surgery and her diagnosis of endometriosis has been confirmed. A reflexologist in Johannesburg who offers a specialised treatment for women suffering with endometriosis referred Charlene to me. The reflexologist was aware of the research project and provided Charlene with my details and introductory letter. I communicated with Charlene and explained to her that the information obtained would form part of my research project and that the sessions would be recorded. Charlene was aware of the implications and agreed to meet with me.

At the time of the interview, Charlene was 30 years old and married with a three-year old daughter. She is currently pregnant with her second child. Charlene has previously worked in accounting, but in September 2009 she resigned and is now self-employed, choosing to work from home where she is able to care for her daughter, and manage her stress levels. Charlene identified cousins that experience fertility problems,

although in the Indian culture these are rarely discussed and are definitely not labelled endometriosis.

The interview was conducted at the interviewee's residence in the northern suburbs of Johannesburg. The environment in which the interview took place was comfortable and quiet and there were no distractions. This facilitated the co-construction of a meaningful dialogue between Charlene and myself.

Table 4.1. Thematic network for Charlene

Basic Themes	Organising Themes	Global Themes
<ul style="list-style-type: none"> <li>• Anger</li> <li>• Cultural avoidance</li> <li>• Societal expectations</li> <li>• Normal vs. other</li> <li>• Isolation</li> <li>• Lack of empathy or understanding</li> </ul>	<b>Infertility as Stigma</b>	<b>Social Functioning</b>
<ul style="list-style-type: none"> <li>• Inability to work</li> <li>• Emotional turmoil</li> <li>• ‘Monster’</li> <li>• Crying</li> <li>• Couldn’t face the day</li> <li>• Frustration</li> <li>• Tantrums</li> </ul>		
<ul style="list-style-type: none"> <li>• Mental changes</li> <li>• Lack of control</li> <li>• Feel psychotic</li> <li>• Destructive behaviour</li> <li>• Youth vs. cranky old woman</li> <li>• Betrayed by body</li> <li>• Visualization</li> </ul>	<b>Fragmentation of mind and body</b>	<b>Transformation</b>
<ul style="list-style-type: none"> <li>• Inability to conceive</li> <li>• ‘Ticking clock’</li> <li>• Can’t deal with normal activities</li> <li>• Anger</li> <li>• Rebellion</li> <li>• Feels like a different person</li> </ul>		
<ul style="list-style-type: none"> <li>• Lack of support or understanding</li> <li>• Cultural opinions</li> <li>• Isolation</li> <li>• Lack of communication</li> <li>• Effort to correct wrongs</li> <li>• Concern for daughter</li> </ul>	<b>Generational legacy of endometriosis</b>	
<ul style="list-style-type: none"> <li>• Myths</li> <li>• Lack of information</li> <li>• Unprepared</li> <li>• Uninformed</li> <li>• Loss of faith</li> <li>• Incorrectly trained professionals</li> </ul>		

## The Generational Legacy of Endometriosis

Charlene comes from a large fertile family. Her parents and grandparents had no difficulty falling pregnant. Due of this, Charlene found the news that she had endometriosis and would not have children naturally earth shattering and unexpected. Charlene commented:

*It was a shot in the dark; it just came out of nowhere. I didn't expect it...*

Her family had not faced fertility problems before and Charlene feels that this meant that her mother overlooked many signs and that her family were not equipped to give advice and guidance with regards to endometriosis and living with infertility.

The impact that endometriosis has had on Charlene's life is tangible. Its influence is complicated and is addressed differently amongst different generations and within the Indian culture. As Charlene stated:

*Because there's so little information around the subject they (her family) obviously didn't know exactly what was wrong with me.*

*I've got cousins who have endometriosis but it's not called endometriosis, they just can't have kids. So there's no name given to it in that sort of circle and everyone just assumed that would be me, you know. I wouldn't have kids and that would be my life.*

This lack of support or acknowledgement led to Charlene developing feelings of isolation. Furthermore, the theme of silence is transmitted from parents to children and even to grandchildren. Charlene expresses deep concern for her own daughter, as she is acutely aware that endometriosis may be hereditary. She worries that her daughter will also have to endure the isolation caused by the disease. When asked whether she worries about her daughter having endometriosis, Charlene replied:

*Excessively. Excessively. Um but I'm actually quite happy that I have – I have information and will be able to notice things with her that my mom did not*

*notice with me and I will get her the help necessary should that happen. I feel that I'm equipped to give her better advice, to point her in the right direction and basically be able to shepherd her, you know. Nobody did that for me and that is – that was huge, you know, not being able to have someone to direct to – a comment or something.*

Charlene evidently is aware of the shortcomings in the communication she received from her parents and community regarding endometriosis. She is also aware of the impact that this can have on a sufferer of endometriosis. Through this experience, she has taken the positive step to remain informed regarding the disease and to break the cycle of silence by communicating honestly and openly with her daughter in order to provide her with the support and guidance she feels was lacking in her own early life.

### **Fragmentation of Mind and Body**

Charlene seems to have experienced a loss of cohesion between her body and her mind. At times she feels completely disconnected from her body, while at other times the mental changes overwhelm her.

*The mental changes that have occurred since being diagnosed with endometriosis. It's sort of turned my life upside down. Its as if the control that you have over what happened in your life is taken away and you feel absolutely powerless.*

*It (taking the pill continuously) turned me into a monster and I'm already quite a moody person, so I honestly used to feel psychotic.*

For Charlene discovering that she was pregnant for the first time was a very traumatic event. Doctors had previously told her that she would never fall pregnant naturally and that she would battle to carry a child to full term. With this expectation the unexpected pregnancy was far from a joyous experience. Charlene was unable to enjoy her pregnancy, as she was consumed with the fear of losing her unborn child. She felt unable to connect to her child, which further precipitated a sense of loss of control.

Immediately following her diagnosis Charlene attempted to run away and hide from the disease. This was because at twenty-three years old, Charlene was unable to comprehend the magnitude of endometriosis and its effects on her life. She was placed on Zoladex injections and experienced menopausal symptoms. Although her body was only twenty-three years old, she was experiencing hot flushes and felt like a “cranky old woman”. This created a rift between her mind and body. She rebelled by binge drinking, going out clubbing and acting out in destructive ways. Charlene used these behaviours to mask the actual pain she was experiencing.

*I felt like my mind didn't belong to me anymore. My body was doing okay at that time; it was my mind that was failing me. It's an extreme sense of – of insanity.*

Charlene also felt that her body had betrayed her. Although this was not her initial reaction to the diagnosis, it emerged when she became engaged and suddenly felt guilty at the limitations that her body placed on her relationship. However, through the adversity and battle within herself Charlene has learnt to take control of her disorder and uses diet and alternative therapies to improve her state of mind. She has also surrounded herself with supportive and understanding friends. She acknowledges that failure to disclose to others can create isolation. As Charlene states “You can be alone in a room full of people”.

*I think my state of mind has improved greatly since then (since she reduced her stress). I wasn't really doing much to change my diet before but I am doing it now and I'm actually seeing results you know.*

At times, Charlene felt psychotic and experienced drastic fluctuations in mood. This led her to question her own sanity and self-identity, creating insecurity and anxiety at the changes she was seeing. She found it very frightening that she no longer recognised herself during this phase and actually used the word “monster” when describing herself.



*I used to feel like – like if someone left a cupboard open or forgot to put the lid on something. I honestly felt like – I could see myself literally tearing things off the wall, shattering everything around me. It was quite insane being able to visualize the psychotic outbreak. I used to scream and shout a lot and you know, just go off in a huff. You're completely irrational. You feel like you're going to do things that you normally wouldn't do and it's quite scary that something can turn you into a monster, literally.*

Changes in self-perception can lead to fragmentation of the mind, as described in the extract above. Although Charlene was aware that her behaviour and mood fluctuations were related to the medication she was taking, this did not alleviate the guilt and frustration that she felt at her lack of control.

On a positive note, the experience of endometriosis allowed Charlene to become better acquainted with her body. She is now able to focus on her body's responses and is acutely aware of any potential problems and warning signs. She no longer takes her body's abilities for granted. The process of endometriosis and its treatments have led her to work with non-invasive, holistic treatments that combat the symptoms. This, in combination with the knowledge and awareness she has gained, has prepared her for the future and she is positive that the disease is manageable.

### **Identity Transformation**

Most women see the ability to bear children as a fundamental right. When this goal is unattainable or in jeopardy, a woman's sense of accomplishment can be threatened (Salzer, 1991). This can be accompanied by a loss of self-esteem and feelings of anger, depression, fear, shock and denial. Charlene experienced feelings of shock and disbelief when she was first diagnosed with endometriosis at the age of twenty-three.

*I was told I would not be able to have kids normally. I – I would have to be um assisted in trying to conceive and I was told that um, there was no certainty as to whether I'd be able to actually carry a child to term and I was 23 years old. I had just been divorced so it was not – it was the worst time in my life –*

*possibly the worst time to be told that there's a clock ticking away and I need to have – or I need to try and have kids as soon as possible.*

Charlene is consciously aware of the change in her identity since her diagnosis of endometriosis. She described herself as a “carefree, quite happy thinking woman” whose life was going in a specific direction until her diagnosis. Endometriosis created a shift in her perception of herself. She not only had to deal with the diagnosis, but was also in the process of recovering from a divorce. During this time she experienced feelings of powerlessness as her life spiralled out of control.

*I think its also affected my mental state as well because I've just become so – like I'm not – I mean, I haven't really been – I can't say depressed, you know, but although it – sometimes it does feel like that. I just cannot deal with it. I can't deal with just normal, simple daily activities.*

For Charlene, the thought that she would not be able to have children made her feel angry and she felt that she was unable to fulfil her role as a woman. She initially rebelled against her disease, acting in a completely irresponsible manner in the hope of drowning the pain. Over time Charlene has come to terms with endometriosis and, through a supportive relationship and the birth of a child, she has learnt to release the frustration and focus on the positive aspects of her life. She has created balance and is grateful for the good days and the blessings she has. However, she remains wary concerning the future.

Charlene acknowledges that she is now a different person to the twenty-three year old who was diagnosed with endometriosis. She has altered her perspective on life, her body and the medical profession. Through this awareness she is finding balance between body and mind and has discovered a passion for helping others who suffer with endometriosis.

### **Infertility as Stigma**

At the age of twenty-three Charlene was told that she had endometriosis and would not be able to have children normally. She was also told that even if she was able to

conceive with assistance there was no certainty that she would be able to carry a child to term.

*The stress of being told something like that so early in life – it was something that was earth shattering, even though I never thought about having kids at the time. But the thing is, you don't want someone to place a restriction on you especially when its something so fundamental to being a woman, you know, you should – its every women's right to be able to have it – have children.*

Charlene, like many women, believes that every woman should have the right to fall pregnant and bear a child (Salzer, 1991). When these rights or dreams were denied, an emotional crisis ensued and Charlene experienced feelings of loss and anger.

*I felt quite angry in fact because I'd been through so much already and I just did not need this right now. Anger which I – I'm still carrying with me which I still haven't dealt with which is quite destructive.*

To make matters worse, this life crisis is not only experienced for a short period of time. Rather, the women suffering from endometriosis encounter a “series of crises” (Salzer, 1991) that are fashioned through the process of doctors' appointments and treatment procedures. When Charlene was asked to describe her treatment plan she replied:

*You've got to basically skip your periods. So it's not natural.*

For many women infertility and gynaecological problems carry a hidden stigma related to shame and secrecy. As indicted in the generational legacy of endometriosis, culturally constructed responses to endometriosis and infertility are embedded in a complicated web of familial, social, personal and medical expectations, all of which can be stigmatizing and damaging (Whiteford & Gonzalez, 1995). For Charlene, this stigma began with her family's response to her disease, and the cultural avoidance of labelling and acknowledging endometriosis.

Endometriosis is an invisible disease. Unlike individuals who suffer from diseases that have obvious external signs, sufferers of endometriosis have no external symptoms. Instead, it is their knowledge of their condition that distinguishes them from others (Whiteford & Gonzalez, 1995). Yet this is sufficient to make them feel inferior.

*Essentially amongst normal women you don't really fit in. You're not like them. They don't have the same concerns you do. It's like you're walking around with this umbrella over your head and everybody else is just running around in the sunshine.*

*I guess you feel quite isolated.*

*You can't explain it to a non-endometriosis person. They think you're quite nuts actually.*

Charlene clearly felt isolated and alienated from the 'normal' population of women who did not understand the pain and symptoms she experienced. She felt as if she had broken some accepted cultural rule and was now classified as other.

### **Relational Patterns**

Endometriosis impacts interpersonal relationships, work, financial, social and recreational activities (Fernandez, et al., 2006). Endometriosis creates disruptions in normal patterns of interaction. It disrupts day-to-day life and is fraught with anxiety.

Four months after meeting her fiancé, Charlene discovered she was pregnant.

*To be told you couldn't have kids and then to fall pregnant, bearing in mind that you according to the doctors you can't possibly carry this child, you're waiting for a miscarriage; it was the most traumatic time in my life. Here I was pregnant, being handed this gift that I did not expect but not really being able to enjoy being pregnant – not feeling that connection to your child because you're so afraid that you're going to lose the child at any point.*

After the birth of her daughter, Charlene discovered that she was again developing cysts. Her gynaecologist placed her on hormonal treatment to combat the potential damage. However, this treatment wreaked havoc on her emotions:

*It (the pill) turned me into a monster. It sort-of turned my life upside down in that I was – I was quite carefree, quite happy thinking, you know my life was going in a specific direction.*

Charlene was unable to deal with normal, daily activities as a result of her fluctuating moods and constant pain.

*If I could help it, I would just stay in bed and not get up at all. The thing that I battled the most with, apart from the pain, is just – just the feeling that, you know, you just cannot face the day. You just cannot wake up. I used to cry a lot. That's possibly the only non-evasive thing you can do, go off into a corner and cry.*

Charlene was fortunate to have a very supportive and understanding husband. She attributes this to their open and honest communication. She has always been honest with him about her illness and made him aware of the possibility that she might not be able to have children. Although her mood swings and frustrations placed additional strain on their relationship, they discussed the problems as a couple and sought help from the gynaecologist.

*I used to scream and shout a lot and, you know, just go off in a huff. You're completely irrational. You feel like you're going to do things that you normally wouldn't do and it's quite scary. I wanted to kill him all the time.*

Charlene and her husband continue to battle endometriosis in a united manner. They refuse to allow endometriosis and its effects to rule their lives and instead focus on the positives, living fully in the moment and taking joy from the small things in life. Charlene's husband supported her decision to resign from her job, which was causing undue stress and worsening her symptoms. This supportive and positive mind set is

vital for women battling with endometriosis as it lessens feelings of isolation and desperation.

In addition to her experience of emotional turmoil endometriosis has also had an impact on Charlene's social life. Immediately after her diagnosis she overcompensated and tried to hide from her disease through denial. She turned to alcohol and clubbing in a bid to avoid the reality of the situation and to gain, if only in her mind, a sense of control.

*I was binge drinking, going out clubbing, doing everything I was not suppose to do. I did it because at that time it masked the actual pain of having to sit down and think about the – the reality of what this illness had brought to my life.*

Having moved past this phase, Charlene now finds that her social life is less active as she has a young daughter. She has accepted the reality of her disease and is grateful for the blessings in her life. This acceptance has allowed her to find clarity and balance in her life.

At the same time, Charlene has embraced her disease and is no longer ashamed of it. She has a wide circle of friends and does not restrict herself to interactions only with those suffering with endometriosis.

It was evident throughout our conversation that Charlene is proactively involved with her disease. She believes that knowledge is power, and that it is important to bring the mind and body into balance. She is currently making use of alternative therapies such as homeopathy, reflexology, exercise and diet to manage the symptoms of endometriosis. She has also expressed an interest in wanting to help others suffering with the disease.

*And I'd like to play a big role in actually helping other women because I think that is you have tools you should – you should, you know, use it to help others.*

## Physician-Patient Conflict

During our conversation, Charlene raised major concerns about the relationship, or lack thereof, with gynaecologists. The medical model portrays physicians as expert, however Charlene's story made it clear that doctors are often not sufficiently trained with regards to endometriosis. This lack of training leads to the perpetuation of myths surrounding the disease.

*I didn't really do much to treat the endometriosis, didn't have much information at the time, was lead on to believe by the doctors who were treating me that it's something that will – you know, it will ease with time.*

*I'm seeing the same gynaecologist (after the birth of her daughter) and was told "Oh, now that you've had a kid, I'm sure the endometriosis is going to get better."*

Her story made it clear that physicians are often reluctant to share information with their patients or to enter into dialogue relating to treatment options. Instead, physicians prefer to dictate the suggested treatment regime.

*When I was diagnosed I was told that it was at stage IV and my bowels were fused to my ovaries. I was told a hysterectomy (at age 23) would be a viable solution. So I was given quite crazy possibilities.*

*Christy: Did they prepare you for that (the Zoladex injections)?*

*Charlene: Mm-mm (indicates in the negative)*

*Knowledge is power. There's very little of that circulating at the moment. I just wasn't given any information. I think that medical professionals – professionals are not given the proper training when it comes to endometriosis.*

This leads to a breakdown of communication and trust between patient and doctor, contributing to an environment where the patient feels obliged to look for alternative

sources of information and support. In Charlene's case, the Internet has helped prepare her for the future and living with endometriosis.

*I guess I've lost faith in the gynaecologist by now.*

Charlene is also concerned at the lack of holistic treatment plans. Gynaecologists offer solutions to the symptoms of endometriosis, but they fail to address the psychological aspects of the disease. In Charlene's story, doctors recommended that she undergo a hysterectomy at twenty-three years of age, but they never discussed the long-term repercussions of this treatment option. They also made no recommendation for mental health treatment prior to making such a serious and permanent decision. Again, when Charlene was placed on Zoladex injections (which replicate menopause in the reproductive system) the doctor did not explain the side effects and the impact that this would have on her everyday life and self-esteem. The physicians seem to feel that these are simply issues that women living with endometriosis should learn to deal with.

*They just focus on the physical side of it, which is not – which is not a complete human being because we're not just made up of a physical body, you know. There is the intangible side to us that affects the physical side greatly. It is something that needs to be addressed.*

*Also, it's quite shocking that there are so few specialists out there.*

Charlene believes whole-heartedly that a holistic approach focused on non-invasive therapy, can help women be stronger and manage the disease better. She also highlighted that shared support through support groups and interaction with other women suffering from endometriosis allows individuals to communicate with other women who understand the experience of endometriosis. She is very concerned and believes that physicians are not providing women and girls diagnosed with endometriosis sufficient support, leading them to lose confidence in the medical system and resulting in unnecessary segregation.



*I feel strongly that endometriosis needs a voice. It needs a louder voice. I can imagine that, as a 23 year-old I battled with it, as a 16 year-old I can imagine what those girls must be going through.*

Charlene expressed her frustration with gynaecologists who often failed to provide her with sympathy. At one stage she felt as though the medication she was taking was creating mental instability, and the gynaecologist who prescribed it calmly advised her that it was expected and that everything was fine. This distressed her and she felt that she should not have to live with the side effects she was currently experiencing. Charlene was extremely frustrated and disappointed by the doctor's response. Anger is frequently directed inwards, resulting in feelings of depression and worthlessness. In the interview Charlene expressed her anger toward the medical profession:

*"It's not fine. It's not fine at all" you know. "I – you're making me feel like a lab rat".*

Coupled with an intense desire to understand what is happening to her body Charlene experiences a sense of frustration at the fact that the world does not try to better understand the difficulties facing women living with endometriosis. Although this frustration has the potential to render her helpless, hope still survives. Charlene's own desire to make some sort of difference has perhaps been born from her own experiences with her family and doctors. She has recognised the need and the urgency to do more to help women with endometriosis. This need to heal and to make things better for herself and others was a recurrent theme in Charlene's narrative.

For Charlene simply acknowledging endometriosis and its effect on her life is not sufficient. She feels that this knowledge needs to be used to benefit others. Through her passion and determination Charlene has found a new outlet for her anger and is focused on taking back control in her life and channelling this new-found control towards others that need guidance.

Three global themes were present within Charlene's story. These global themes were labelled social functioning, transformation and the relationship with the medical community and are discussed below.

**Global Theme: Social Functioning**

Charlene's struggle with belonging and isolation and her desire to provide energy for others relates to feelings of participation and social functioning. Her social functioning refers to her process of involvement with others and her participation in interpersonal exchange. In order to function effectively in any society it is important to be accepted and to understand the rules of that society. Within the context of endometriosis, Charlene gained a sense of acceptance through her relationship with her husband. This acceptance helped her to learn how to engage with others suffering from the disease. Through improving awareness of the disease amongst her circle of friends, Charlene began to demolish the stigma attached to endometriosis.

**Global Theme: Transformation**

Charlene's difficult relationship with her parents and her experiences with endometriosis have moulded the person she has become. Charlene describes the way in which she has accepted responsibility in her journey with endometriosis and now takes an active role in choosing her treatment and remaining educated regarding the available options. Endometriosis has also provided her an opportunity to transform a family narrative and to establish a new context for her daughter and future children. Transformation refers to a change in nature, form, appearance or character. Charlene's life has been characterised by many challenges, instability and change. Nevertheless, she has adapted to these fluctuations and has recreated her identity based on her experiences and reality. This has helped to foster an environment in which she feels able to grow.

**Global Theme: Relationship with the Medical Community**

Health professionals have the ability to empower or disempower women suffering from chronic diseases. Charlene struggled to preserve the status quo with her doctors and was ultimately unable to build a stable relationship with the formal medical community. This medical support structure is missing from her life and Charlene compensates by using her abilities, insights and personal strength to create a stable

reality and understanding for herself. This process allows Charlene to preserve her self-worth and happiness in the face of an environment that often oppresses women or labels them as weak.

## **Anne's Story**

### **Background Information**

Ten years ago Anne began experiencing severe period and lower back pain. Her gynaecologist decided to investigate via laparoscopic surgery and diagnosed endometriosis. He removed the lesions and she remained symptom free for two years, when a lump was discovered in her stomach during a general check-up. Anne was referred to a general surgeon, who performed a biopsy on the lump. The surgeon was unable to determine the cause of the lump and decided to operate to remove the lump. The surgeon removed a mass of approximately 10 to 15 cm, which he determined to be endometriosis that had grown into the scar from her last caesarean section. The gynaecologist then placed her on hormonal injections (Nur-Isterate) to help reduce the possibility of further endometriosis growths. Anne experienced a particular problem with weight gain whilst on these injections, and when her husband had a vasectomy she opted to stop all hormonal treatment for endometriosis.

My husband, a physiotherapist working in Johannesburg, referred Anne to me. He had been discussing my research at work and she had told him that both she and her daughter struggled with endometriosis and would be happy to participate in the project.

I sent Anne my introductory letter and provided her with written details regarding the research. I explained the process of the interviews and explained that the information obtained would form part of my research project and that the sessions would be recorded. Anne agreed to meet with me and was open to discussing all aspects of endometriosis with me.

At the time of the interview, Anne was 48 years old. She is married with two daughters and works part time as a bookkeeper in her husband's business. Anne's

mother had gynaecological problems, including heavy bleeding, and had a hysterectomy at the age of 40. Anne believes that if her mother were treated today she would be diagnosed with endometriosis. Anne's daughter has also been diagnosed with endometriosis. Anne is a breast cancer survivor, and has now entered menopause as a result of the chemotherapy treatment.

The interview was conducted at Anne's residence in the northern suburbs of Johannesburg. She was extremely welcoming and forthcoming during our conversation. The environment in which the interview took place was comfortable and quiet.

Table 4.2. Thematic network for Anne

<b>Basic Themes</b>	<b>Organising Themes</b>	<b>Global Themes</b>
<ul style="list-style-type: none"> <li>• Connection with body</li> <li>• Empowerment</li> <li>• Positive outlook</li> <li>• No shame</li> <li>• Acceptance</li> </ul>	} <b>Identity through self-awareness</b>	} <b>Transformation</b>
<ul style="list-style-type: none"> <li>• Guilt</li> <li>• Positive response</li> <li>• Open communication</li> </ul>	} <b>Generational Legacy</b>	
<ul style="list-style-type: none"> <li>• Lack of concern from others</li> <li>• Support by partners</li> <li>• Lack of education</li> <li>• Myths</li> <li>• Misconceptions</li> </ul>	} <b>Societal Interactions</b>	} <b>Social Functioning</b>
<ul style="list-style-type: none"> <li>• Frustration</li> <li>• Annoyed with side effects</li> <li>• Pain</li> <li>• Anxiety</li> </ul>	} <b>Frustration inciting Healing</b>	
<ul style="list-style-type: none"> <li>• Meaningful relationship</li> <li>• Lack of emotional support</li> <li>• Trivialization</li> </ul>	} <b>Physician-Patient Relationship</b>	
		} <b>Relationship with the Medical Community</b>

## Identity through Self-Awareness

Our perception of who we are is determined by our roles, the way in which we see ourselves and the ways in which other people see us. Having suffered from endometriosis, the threat of a mass in her abdomen and cancer, Anne has become acutely aware of her body and its nuances. When I asked her whether endometriosis has allowed her to connect more deeply with her body, Anne replied:

*Oh, definitely. You know when something's not right. Oh definitely.*

She has adapted a positive attitude and through her struggle with her daughter's diagnosis of endometriosis, Anne has accepted the role of rescuer. Assisting her daughter in her struggle helps empower Anne and bring her a sense of control and purpose.

*I was quite worried about how we're going to deal with this (after her daughter's second laparoscopic surgery).*

When faced with the news of her recurrent and aggressive endometriosis, Anne's daughter suggested that perhaps she should consider a hysterectomy. Anne refused to accept this outcome for her daughter and fought to help her daughter maintain her quality of life and keep all options available. It is almost as if she feels that she can determine her daughter's disease progression through sheer willpower.

*And I said to her, "No, you don't. We're still going to be able to have children". So I've been very positive with her, saying, "We're going to have children. He says your tubes are fine and we're going to do it."*

Anne has fought to keep her identity over many years and has not allowed depression or self-pity to become part of her identity.

*I discuss it (endometriosis) openly. No shame factor. You take each day as it comes, you know, and you just deal with things as they happen. So ja, I think*

*you've just got to stay positive and probably work at it, you know, every now and again.*

Anne has developed strategies to gain control or mastery over endometriosis. One of the strategies involves comparing her own situation to the situation of someone less fortunate.

*And I think I'm maybe saying this now since I've had breast cancer, which is more of a serious issue. So I think that's – that was fine. And I think I'm most probably more relaxed with that (endometriosis), you know, having had cancer.*

Anne's story reflected an acceptance of endometriosis. She has come to terms with the reality of the disease, particularly in the face of her greater struggle with cancer. This acceptance also provides Anne with a sense of control and allows her to continue with her lifestyle. Endometriosis has become part of her life, rather than the ruler of her life.

### **Generational Legacy of Endometriosis**

Women diagnosed with endometriosis often experience feelings of guilt, The emotional upheaval following diagnosis can place undue pressure on the woman and her partner, often leading to internalization of guilt and shame. Woman may feel damaged, defective, physically unfit and guilty (Abbey, et al., 1991).

In my conversation with Anne it was clear that Anne did not experience feelings of guilt or shame in relation to her experience of endometriosis. For her a large part of this was the fact that she has already completed her family when she was diagnosed, so her fertility was never called into question. She thus never experienced the guilt associated with gender role expectations within society, and never feared that she was letting her partner down.

*I wasn't going to have another – another child. I'd had my two. But it'd be different if I hadn't had children.*

However, Anne does express feelings of guilt when speaking of her daughter. Anne's knowledge and experience with endometriosis make her aware of the impact of the disease. She is also aware of the genetic component of endometriosis. For this reason, Anne feels guilt for passing endometriosis on to her daughter and feels guilty that she is not able to help ease the difficulties that her daughter is facing.

*It concerns me. I'm actually very worried about her. I feel bad that it has happened to her, and at such a young age. I think maybe because she's so young I do feel – ja, maybe I do feel a bit guilty because it – she's so young. I think if she was older and she'd had her children I'd think "well that's okay". I think I worry more about her than anything else, what is going to be outcome.*

When recalling her daughter's initial diagnosis at the age of 16, Anne remembers her daughter's immediate reaction:

*He (the gynaecologist) turned around and said its heredity, so she said "Oh, thanks Mom".*

Anne continually works to dispel the legacy of silence by communicating openly and honestly with her daughter. She encourages her daughter to educate herself regarding the disease, and to maintain a positive outlook for the future.

*When she's feeling a bit down, I always try and give her the positive side of it that "it's going to be all right and it will work out".*

### **Societal Interactions**

Endometriosis is shrouded in myths and misconceptions. Society's perceptions of gender roles and fertility often isolate women who suffer from gynaecological problems. These interactions can influence a woman's self-image and her identity within society.



Research has shown that physicians have a large impact on how women view themselves and on their ability to cope with their disease. Unfortunately, physicians often underestimate the amount of information they should share with their patients in order to build a relationship of trust. In many cases, patients see this as a lack of acknowledgement of their personal suffering, which leads to them feeling marginalized. After Anne's daughters first operation Anne met with the doctor. Anne recounted this interaction:

*I wouldn't say we were too concerned then because when we went in and did the laparoscope, that it's "Ag, not – not bad. We'll put her on Diane and everything will be sorted out and that."*

During our conversation, it became clear to me that Anne's husband is very supportive and understands the importance of open communication within the family. He accepts responsibility in helping her and their daughter come to terms with their disease. When I asked her about his involvement, Anne replied:

*I must say that my husband's actually very concerned. I think he has been quite worried. He actually came with to speak to the gynae – he's like that. He's always been quite involved if anybody's been sick and that sort of thing. He's also very concerned and gives her (their daughter) the positive approach. We try not to look at the negatives.*

When Anne's daughter was diagnosed with endometriosis, Anne became acutely aware of the lack of education amongst teenagers and their mothers relating to endometriosis. Many mothers still hold to myths about the use of birth control and are ignorant in their approach to gynaecological health precautions for their daughters. This experience has led to Anne adopting the role of an educator, thereby gaining a sense of control over both her own and her daughter's disease. When asked whether people know enough about endometriosis, Anne replied:

*No, I'd say they don't. Some of them don't know anything about it, but I think they're finding it out with their children because I think it's becoming a common thing in young children. And the gynae has said to me that he's*

*finding it very common in girls from age of 16. And they will come, um they'll say, oh you know their daughter's really got terrible period pains and heavy periods. "Do you think I should take them to the doctor". And I would say, "Yes, go. Go to a doctor. Go to a gynae, have it sorted out because they can help it."*

*I think a lot of moms at the stage (when her daughter was diagnosed), were horrified that she was put on the pill because how – you know, you now are asking for trouble. I said, "No, you're not." I said, "If it's going to help, it's for her benefit. I'm not thinking whether she's going to go out and sex or whatever". I mean, you don't have to put them on the pill for that anyway. So, I think they don't – they're not informed. People don't feel enough about it.*

Anne seems to have formed a co-operative relationship with her physician in managing her disease. This relationship is built on trust. Anne also has a supportive network of family and friends that help her to cope with her disease and to focus on remaining positive. Through her interactions in society Anne is also able to focus on educating others, which provides her with a sense of control and purpose.

### **Frustration inciting Healing**

Women who suffer from endometriosis regularly express frustration at the lack of medical breakthroughs related to the disease and the associated lack of education and awareness. Women also express frustration at the unending merry-go-round of treatments and doctors' appointments, non-relenting pain and anxiety. This frustration has the potential to render women helpless. However, Anne has recognised the need to stay positive and do more. She is determined to make a difference in not only her daughter's life, but in the lives of other young women through educating their mothers.

*I was annoyed about it. Look, I've always been on that – that battled with my weight but I put on quite – quite a bit of weight and I thought, "Age, this is going to make me better and not have the endometriosis again, well then maybe 'I'll deal with it". But there were times I'd say that it did get me down.*

When the doctors discovered the lump in Anne's abdomen she was extremely anxious and in extreme pain. She described this experience:

*Um, I'd say then I was worried, but once I knew what it was, I think I was more of – relief that it wasn't something more serious and that you could actually deal with it.*

The threat of more serious illness seems to have helped Anne find a way to accept the pain and frustration she experienced as a result of endometriosis. She uses the information she gained during her personal struggle to help her daughter in her own struggle with endometriosis.

### **Physician-Patient Relationship**

For Anne her connection and relationship with her gynaecologist made her experience with endometriosis bearable. Her trust in her doctor seems to have strengthened her and gave her the courage to cope.

*I think the sun shines out of my gynae, I really do. I love him to bits. So – and I mean – I've been with him 25 years. So I'm really happy with him. He's happy to listen, he really is. He does all his diagrams and he takes his books out and he's excellent.*

This connection to the professional is significant in the control and acceptance of endometriosis. The acknowledgement of her experience and the advice provided helped to establish a meaningful relationship between Anne and her gynaecologist.

However, Anne did acknowledge that her gynaecologist failed to address the emotional aspects of endometriosis and sometimes trivialised the side effects that she experienced during hormonal treatments. She also highlighted the need for physicians to adequately prepare women for potential side effects before placing them on treatment protocols in order to alleviate feelings of uncertainty and undue stress.

*I think it's when you go back and say to them, "You know, I've put on weight" or "I've done this", then he'll say "Yes, it is a side effect, but it's something that you have to deal with". That's what they tell you, "its something that you have to deal with".*

*I think it would be better if they do tell you upfront that this is what's going to happen, these are the possible side effects, they might happen or they may not happen, so that you actually know what's going to happen. And you prepare yourself. I think they do when you go for chemo, they tell you straight out, "these are your possible side effects. It can happen. It might not happen". So you actually know when they come. So I think they should prepare you better and they should tell you.*

Anne's story includes three global themes, namely: Participation, transformation and the relationship with the medical community.

### **Global Theme: Participation**

Anne's relationship with others involves a process of participation. Anne describes how non-sufferers fail to understand or show empathy for women living with endometriosis. She is particularly concerned about the lack of education and awareness that is prevalent amongst teenagers and women, fostered by myths and misconceptions. Through her relationship with her husband and family, Anne has gained a sense of belonging and acceptance. Her relationships with her daughter's friends and mothers have provided Anne with an opportunity to engage with an outside audience using her energy and knowledge.

### **Global Theme: Transformation**

Anne has been through many difficult and demanding experiences and has demonstrated her personal strength, adaptability and capacity for growth. Anne describes her journeys with endometriosis and cancer as contributing to her personal growth and the development of her character. Anne experiences a sense of

gratification and meaning through her relationship with her family. Helping her daughter fight her battle with endometriosis provides Anne with a sense of purpose.

### **Global Theme: Relationship with the Medical Community**

Anne was able to build a healthy and stable relationship with the medical community, and feels free to express her opinions and her personal 'expert' knowledge. She also recognises the reality of conflict within the doctor-patient relationship and acknowledges that her doctor is not perfect. Anne is thus able to maintain and control her world due to her awareness of endometriosis and her own body. Having faced and survived breast cancer, Anne has created a satisfying milieu in both her work and family life and experiences stability, security and support.

## **Estelle's Story**

### **Background Information**

Estelle was introduced to me by a fellow psychology Master's student at the University of South Africa. As a form of peer review the research topics and objectives were discussed during a Master's class. This fellow student's best friend had recently been diagnosed with endometriosis and she suggested that I contact her. I contacted Estelle via email and explained the research project to her. I also explained that her experiences would form part of my research project and that the sessions would be recorded. Estelle was very excited at the prospect of taking part in the research and agreed to meet with me.

At the time of the interview Estelle was in a serious relationship and was living with her boyfriend in the northern suburbs of Johannesburg. She works as a marketing assistant and is completing a degree through the University of South Africa.

Estelle's symptoms began about three years ago when she started experiencing extreme pain from the waist down after sexual intercourse. She thought that she might have a problem with her digestive system and decided to consult a gynaecologist. The gynaecologist attributed the pain to Estelle's blood sugar levels and did not

investigate the possibilities any further. A year later Estelle returned to her doctor, still experiencing excruciating pain. The gynaecologist dismissed her and advised her that there was nothing wrong. At the beginning of 2010 Estelle experienced a sharp pain in her right ovary and made an appointment to have a scan at a local hospital radiology department. The scan showed an 8cm cyst in her ovary, which the doctor stated was common and not be a cause for concern. Frustrated, Estelle turned to her mother's gynaecologist, who suspected that she might have endometriosis. At the age of 23, Estelle was admitted to hospital to have the cyst removed by means of laparoscopy. The doctor later confirmed that he had detected endometriosis.

Table 4.3. Thematic network for Estelle

<b>Basic Themes</b>	<b>Organising Themes</b>	<b>Global Themes</b>
<ul style="list-style-type: none"> <li>• Lack of intimacy</li> <li>• Romance</li> <li>• Impaired communication</li> <li>• Shame</li> <li>• Changes in femininity</li> </ul>	} <b>Sexual Dysfunction</b>	} <b>Emotional Well-Being</b>
<ul style="list-style-type: none"> <li>• Disappointing others</li> <li>• Resolution</li> <li>• Denial</li> <li>• Keeping others happy</li> </ul>	} <b>Denial by putting others first</b>	
<ul style="list-style-type: none"> <li>• Fear of the unknown</li> <li>• Fear of being judged or labelled</li> <li>• Fear of physical changes</li> </ul>	} <b>Fear</b>	
<ul style="list-style-type: none"> <li>• Isolation</li> <li>• Connection with mother</li> <li>• Embarrassment</li> </ul>	} <b>Relational Issues</b>	} <b>Social Functioning</b>
<ul style="list-style-type: none"> <li>• Selfish</li> <li>• Not wanting children yet</li> <li>• Body makes decisions</li> <li>• Avoidance of future</li> </ul>	} <b>Intellectualisation vs. Understanding</b>	
<ul style="list-style-type: none"> <li>• Frustrated</li> <li>• Disillusioned</li> <li>• Unable to question physician</li> <li>• Shock</li> <li>• Dictated to</li> <li>• Lacking information</li> <li>• Lack of empathy</li> </ul>	} <b>Physician-Patient Relationship</b>	} <b>Relationship with the Medical Community</b>

## Sexual Dysfunction

Endometriosis can place significant pressure on emotional and sexual relationships of sufferers. The disease can give rise to disruption and conflict within a relationship. Chronic pain experienced during or after sex can lead to women emotionally withdrawing from their partners. Men may misinterpret this withdrawal as rejection, and this places unnecessary strain on the relationship (Johnson, 2003).

It was clear during our discussion that the lack of intimacy between Estelle and her partner was causing her significant distress. She was extremely focused on trying to keep him happy, while still trying to come to terms with her disease and the pain she was experiencing. She said:

*Well I can tell you it's had a big effect on my sex life. Um, I mean you know, my boyfriend and I have been together for two years and it started since we got together. And every time afterwards I would go to the bathroom and lie on the floor and you know, almost want to die of the pain, you know, and that would ruin the whole moment.*

*I've noticed in the last few months of our relationship we're not as connected if we haven't you know, had sexual intercourse for a while and it does affect the relationship badly because then, then I don't know if, you know, a marriage will last through that, you know.*

*The element of romance and it's, you know, fun and whatever has gone out the window completely, for now.*

This lack of connection has left Estelle with feelings of isolation. She is unable to share her experiences and suffering with her partner. This inability is partly fuelled by her fear that he will no longer wish to stay with her.

*I don't want to do it (sex) anymore because I just don't want to experience that pain. So it has affected my relationship a lot, because it's a big part of a relationship, I guess. I mean, we do want to get married eventually but he is –*



*he's worried that if our sex life is like this now, how will it be once we're married. But the thing is it's – it's psychologically I can say it's – it's really – I don't tell him. I'm – I don't want to tell him I'm scared I'm going to have the pain because that ruins the moment.*

When I asked her whether she feels that her boyfriend would not understand, she responded as follows:

*I think he's a very understanding person, but he will then say "Well, how do you get over that" you know, and then I'll say "Well, I don't think I can". So there's a kind of block. We can talk about it but then, what's the outcome. So he understands but I think he wants it resolved rather than understanding and communicating about it, because he can't live without sex and you know, and he can be understanding to a point.*

Endometriosis has had a significant impact on Estelle's sexuality and has led to feelings of shame. She expressed fear at the possibility of not being able to have children and felt that her femininity had been taken away from her. She made the following comment:

*But then I don't want to worry about not having children. You know, I want to be a real woman. I want to be able to say that I can have children easy-peasy and no problem.*

### **Denial by Putting Others First**

Estelle makes use of the defence mechanism of denial in order to deal with her endometriosis. This denial is currently shielding her from the initial devastating pain and is providing her time to assimilate what has happened. Hopefully this will be a temporary anaesthesia (Salzer, 1991).

However, this denial could prove to be problematic if Estelle does not adapt to reality and address the potential consequences of her diagnosis. During our conversation, it became evident that Estelle's denial is grounded in her concerns with regards to her

relationship and the dependability of her partner. This is sustained by her partner's lack of support, her feelings of guilt and the lack of communication between them.

*I'm really scared of disappointing people and losing people and – especially my boyfriend and um, it's a constant stress.*

*He (her boyfriend) wants it resolved rather than understanding and communicating about it.*

Estelle is also extremely concerned with disappointing people and appears to feel that endometriosis is something that she has brought upon herself.

*I'm ashamed and scared that I won't be able to have children. And I think that stress of thinking of the fact that I won't be able to have children and disappointing my mom, disappointing my dad and my grandparents and my boyfriend and everyone – it just no. I can't deal with that.*

It is clear that Estelle's denial is rooted in her desire to make others happy even when their happiness is at her own detriment. In her attempt to avoid disappointing others, she may be distancing herself from the full implications of endometriosis.

*I don't want to even think about it (not being able to have children) right now, you know. Marriage is my next step and then maybe I'll start thinking about starting – because it's just too much stress.*

When I asked Estelle whether her physician had checked her fertility status she replied:

*But I didn't think about that because there's nothing in my family that says, you know, you can't have children. So, I mean, it sort of struck me as “okay, fine I've got it (endometriosis) now but its fixed now. I'll be fine”, but then I think, “well maybe it's not”, and that scares me now.*

Estelle's denial currently seems to help her cope with the vast amount of information and potential consequences of endometriosis. This denial provides her with a refuge so that she can continue her life in the manner in which she wishes. She appears to believe that she will worry about her disease at a later stage when she feels ready.

### **Patient-Physician Conflict**

When faced with chronic pain patients usually turn to medical professionals for acknowledgement of their symptoms and guidance through the treatment process.

Anger is commonly directed towards the gynaecologist, particularly when diagnosis is not made quickly. Although Estelle never explicitly indicated that she was angry at the misdiagnosis of her disease by the first doctor, it was clear that she was extremely frustrated that she had to live with the pain for such an extended period of time.

*I could feel and thought, "No, there's something wrong". After that I broke down in tears and I walked out because nothing, you know, had been resolved. Then I felt I was – ah, I was going to die because this pain was – I couldn't deal with it anymore.*

Furthermore, Estelle was disappointed with the medical professionals' expert knowledge and the lack of acknowledgement of her symptoms. This led her to feel disillusioned with the physicians. She no longer trusts the opinions of her physicians and instead turns to her mother for advice.

*But then I believed her because she's a doctor so I can't, you know, just say, "Well no, you're wrong."  
I was in shock (after being diagnosed) because I'd thought maybe – you know, what was the cause and my doctor couldn't even say that.*

When asked about the treatment options she had been offered by the doctor, post surgery, Estelle replied:

*Yes, I have to skip my period every month, I – every second month for the rest of my life. So that's not very fun. It's also added stress because now I'm like "ooh, must I take it this month. I forgot. Did I do it last month" you know. I have to constantly think about that. And I'm like, "Well is this really gong to help. And I'm like "Well, great but why? Why is this helping?" You know, he didn't explain to me in the future.*

Estelle's comments in this quote are similar to those experienced by many women. Doctors often dictate treatment options to their patients without entering into a conversation with them. This creates anxiety and anticipation concerning what to expect and often leaves the women with questions about the future.

Now that she has developed a relationship with the gynaecologist recommended by her mother, Estelle remains unsure and is still lacking information on her disease. This demonstrates just how often medical professionals are remiss in sharing their knowledge about endometriosis. Furthermore, doctors often fail to acknowledge the emotional and psychological impact of endometriosis.

*I mean, he sort-of explained to me, but I walked out still not sure of what it (endometriosis) really was. I'm still not actually very sure, you know. I think he was not impatient, but I think he has to explain it to a lot of people so obviously he didn't think that he needed to explain it to me that in depth.*

*I was literally for the check up I was in and out in 10 minutes. Nothing. It was, "Okay, you're fine. Cool. How was the recovery? There you do. See you in a year."*

At times, doctors trivialize endometriosis, making women feel as though they should be able to cope with the symptoms and side effects. Estelle made the following comment:

*Um, I felt, you know – in the beginning when I found it I was like "what did I do to deserve this", you know, but then I thought because the doctor had made*

*it like it's common and happens a lot you know. I felt "Okay, well if everyone else can deal with it, then I can deal with it" you know.*

Estelle has also found it difficult to build a close relationship with her doctor, as he has shown little empathy towards her and has never addressed her as a holistic being.

*But he hasn't made me feel special saying, "Okay, now you as a person, let me help you", you know. Now he thinks, "Oh well, everyone else has it, you can deal with it. Next one", you know.*

*I want him to sit with me and say this is why it happened, this is what will happen in the future, maybe this will come back, or maybe, I want him to really be able to talk to me and not me being shy to ask him.*

## **Fear**

The diagnosis of endometriosis is frequently accompanied by feelings of fear. Estelle fears the life-long physical consequences of the disease but also experiences fear in various other spheres of her life. However, Estelle is determined to not allow this fear to control her.

### **Fear of the unknown.**

Endometriosis is unpredictable and many women experience a fear of the unknown. When Estelle first consulted with a physician she was afraid that something was seriously wrong with her. She describes this feeling as follows:

*I had a horrible excruciating pain all over – from my waist down to – into my legs every time I had sexual intercourse and it was every single time afterwards. I could feel and I thought, "No, there's something wrong".*

Once a provisional diagnosis was made and Estelle was booked for surgery, her fear escalated to include anticipation of the laparoscopic procedure. She did not feel adequately prepared and was unsure of what to expect from the surgery.

*I don't know what was the cause; I don't know what to change about my life. It's constantly in the back of my mind, that pain and that fear of having pain again because it really – I think pain traumatises you in a way and that pain was excruciating. So it's always in the back of my mind.*

Estelle has experienced recurrent symptoms since the operation, and has now developed a fear of the future. She said:

*Because no fine, I've gone for the operation and it seems to be fine, but I'm still experiencing some of the pain, not to the full extent, so I'm scared. I'm actually scared I'm going to live with that kind of fear for the rest of my life.*

Despite the advances in medicine and all the available treatments for endometriosis the progression of the disease remains unpredictable, resulting in feelings of powerlessness.

### **Fear of being judged or labelled.**

Many women diagnosed with endometriosis fear being labelled or judged and worry that the disease will alter people's perceptions of them. Estelle's was worried about being labelled as weak or inconsiderate and therefore tried to hide her pain from others. She has also not been able to share her fears and real feelings about endometriosis and its effects with her partner.

*The thing is I've felt pain now again so I know that it's not completely gone, but I don't want to say anything yet because I don't want to curse it.*

*I also want to just call him (the doctor) – be able to just pick up the phone and call him and say, "Listen, I felt this the other night. Is it normal" – you know, but I'm scared because he will think, "Ag, it's normal. It's so common. He deals with it every day of his life. He doesn't want to deal with another, you know, paranoid patient". You know, I don't want to sound paranoid.*

Estelle is also afraid to share her experiences with friends and is scared that she will bore them by talking about her disease. She prefers to retreat into silence, and copes with endometriosis through avoidance. She said:

*No one really understands that pain except for my friend that has endometriosis. So, it was really hard for me – to even tell my boyfriend, you know. It was frustrating to think that no one really understands that the pain that I went through and the psychological effects of it by, not saying – not being able to talk about it.*

Her fear of being labelled or judged is thus accompanied by silence. Estelle and other sufferers use silence as a coping strategy, adopting a façade and not allowing others to become close.

#### **Fear of physical changes or disability.**

Endometriosis is associated with chronic pain, sexual dysfunction and physical disability. The unpredictable nature of the disease means that symptoms can progress or complications can arise at any time.

Estelle fears that her sexual relationship with her partner will change. She commented as follows:

*When I see my boyfriend, when I speak to him, you know, whenever he gets a little bit flirty with me then I'm like "pain". It's just it's a trigger in my head. But it's subconscious, I think but it does put extra stress on everything else.*

*We were very sexually active in the beginning obviously, but then – now after like the pain got worse and worse, I was like "I don't want to do it anymore because I just don't want to experience that pain".*

Estelle also fears the possible complications of endometriosis, such as infertility. The possibility that she may not be able to have children leads to high levels of fear and

raises concerns about her relationship and whether her partner will be able to accept this.

*Now I'm scared that I won't be able to have children. You know, I want to be a real woman. I know that my boyfriend wants children and – and if we don't have children he will not stay with me.*

Estelle had only recently been diagnosed at the time of the interview and it appeared that she was making use of avoidance in order to contain her fear. She was not yet able to accept the long-term implications of endometriosis and was not positioning herself as an expert on her own condition. However, Estelle is trying to protect that which is meaningful to her, such as her self-image and identity.

### **Relational Issues**

Estelle suffered severe symptoms for three years before a definitive diagnosis was made, leading to feelings of isolation and frustration. During this time she turned to her mother for support and guidance. This support helped Estelle gain a sense of control over her situation. She said:

*Well my mom, she's very into gynaecology, so she was very helpful in the sense that she could talk to me about things and she would actually um, you know, she would call the doctor when I was – during – going through recovery. So she really helped me through that. She explained why I have certain pain and she actually also showed me a diagram of where it was and what is this and where the layers were. So she explained everything to me, actually more than the doctor did. So I felt – so if I didn't have my mom then I would – I wouldn't have anything.*

However, Estelle experiences a disconnection from other members of her family and her friends. She feels that they do not fully understand the disease or the problems that she experiences.



*My dad gets very uncomfortable, you know. My grandparents and so forth, they – I think because it's so common and it's fine and it's not really serious, they don't really, you know, fuss about it.*

*I would chat to my friends and say "Listen I don't know what's going on but it's this pain afterwards. What do you think it is?" And they came up with the strangest ideas. Even a friend of mine said, you know, "Maybe it's a psychological pain". No one really understands that pain except my friend that has endometriosis.*

Estelle found that connecting to other endometriosis sufferers made the process bearable and allowed her to share the responsibility of suffering. She no longer feels so alone in her fight with endometriosis. Neal and McKenzie (2010) state that peer resources provide validation for endometriosis sufferers that differs from the validation received from other sources. These peer resources also provide desperately needed social support. Estelle said:

*And it felt really nice to be able to connect to someone that had it and know – sort of what I was going through because she also had the pain, also had everything.*

Estelle expressed her frustration at society's lack of knowledge about endometriosis and stated that she would enjoy participating in a support group. However, Estelle stated that it was very difficult to find endometriosis support groups.

### **Intellectualising versus Understanding**

Women suffering from endometriosis often try to learn more, find out additional details and build a knowledge base. This need for intellectual knowledge allows them to feel like experts in the field and to gain some control over the progression and treatment of their disease. However, having the facts is not the same as truly understanding the disease and its impact. Coming to grips with suffering is a long-term process.

My conversation with Estelle led me to conclude that she is currently intellectualising her condition. She also avoids thinking about or planning for the future, as she is not ready to address the long-term implications of endometriosis. When asked about how she feels about having children in the future, Estelle replied:

*My doctor said, you know, I'll be able to have children. So I mean, I don't feel any different at the moments. I don't want to have children because, I'm a bit selfish at this point in time and I think it's going to cause a lot of stress. I would rather not have kids at this point in time, if I think about it in the future but I know that my boyfriend wants children – and if we don't have children he will not stay with me.*

*It's up to my body, you know. My body can decide no-no, you go again and um I might not be able to have children and – I think its sort of unrealistic thing for me at the moment because my parents and my mom and my grandmother, everyone's always been, you know, they've always been fine. So it's sort of like, "Well, why would I be the first one not to have children?"*

In an attempt to cope with the uncertainty of endometriosis, Estelle avoids thinking about the ways in which the disease will impact her life in the future. She does not understand the possible ramifications and has not educated herself concerning the treatment options available. Estelle is still in the process of learning to understand her disease.

*Well, I mean, I haven't really thought about it that far along. I mean thinking about it for the rest of my life scares me. I mean, having to skip my period every second month for the rest of my life, I mean when he said that I was like, "okay, great", but now I don't think 20 – 30 years down the line, I think 5 – 10 years, you know.*

Estelle can only come to a full understanding of endometriosis when she fully accepts its possible implications for her future. Managing her awareness of endometriosis and her relationship with her physician might provide her with the sense of control that she is currently missing.

The organising themes evident in Estelle's story are emotional well-being, social functioning and the relationship with the medical community.

### **Global Theme: Social Functioning**

Estelle's struggle with isolation and belonging and her energy exchange with others relates to her feelings concerning participation and social functioning. Acceptance is needed in order to participate in interpersonal contexts. Estelle uses avoidance to cope with her diagnosis, and this means that the people around her are unable to fully accept her. In particular, this has led to a sense of disconnection from her partner. Talking to other sufferers has helped Estelle gain a sense of belonging and acceptance. She now needs to learn how to engage with others in relation to her disease.

### **Global Theme: Emotional Well-Being**

Estelle's fear, denial and sexual dysfunction influence her current identity crisis. Estelle's lack of intimacy with her partner has created a rift between them and has influenced her sense of femininity. This directly assaults her identity and self-image. Estelle is also consumed by fear of rejection, judgement and physical changes. In conjunction with feelings of anxiety and denial this fear has led Estelle to feel ashamed and isolated. She is unable to find the emotional support that she craves and experiences diminished self-worth, self-understanding and a loss of identity.

### **Global Theme: Relationship with the Medical Community**

Estelle's struggle to build a stable relationship with the formal medical community has been the result of a series of misdiagnoses and miscommunications. The lack of this support structure has led Estelle to turn to her mother for strength. Her mother helps her to create a stable reality and understanding of herself. Estelle experiences feelings of disillusionment and disappointment in the medical fraternity. However, Estelle does not yet feel confident enough in her expert knowledge as a sufferer to question her doctor. Estelle is able to maintain control over her world by allowing the

doctors to make the decisions for her thus releasing her from responsibility at this point in time.

## **Kaitlyn's Story**

### **Background Information**

Kaitlyn's battle with endometriosis started at the age of 15. She was experiencing very painful and heavy periods, and when the gynaecologist determined that these were not due to cysts he recommended surgery in order to conclusively diagnose endometriosis. After the operation Kaitlyn continued to use the contraceptive pill to help alleviate her symptoms. Five years later her symptoms returned, leaving her in excruciating pain. She went in for her second laparoscopic surgery in December 2009. During this surgery it was determined that her endometriosis had progressed to stage III. The gynaecologist raised concerns regarding her fertility after the second operation, and placed her on hormonal injections designed to combat the symptoms and severity of endometriosis.

My husband, a physiotherapist in Johannesburg, referred Kaitlyn to me. During a discussion at work, her mother advised him that both she and Kaitlyn struggled with endometriosis and suggested that they would be happy to participate in my research.

I sent Kaitlyn my introductory letter and a written introduction to the research. I explained the process of the interviews and informed her that information obtained would form part of my research project and that the sessions would be recorded. Kaitlyn agreed to meet with me and was enthusiastic to share her story. She wants to heighten awareness concerning this disease, particularly amongst younger women.

At the time of the interview, Kaitlyn had just turned 21 years old and was single. She worked as a beautician at a reputable salon, and has since opened her own salon in Fourways, Johannesburg.

The interview was conducted at Kaitlyn's residence in the northern suburbs of Johannesburg. The environment in which the interview took place was comfortable

and quiet, without distractions. Kaitlyn openly discussed her experiences with endometriosis and displayed considerable maturity in her handling of the disease.

*Table 4.4.* Thematic network for Kaitlyn

<b>Basic Themes</b>	<b>Organising Themes</b>	<b>Global Themes</b>
<ul style="list-style-type: none"> <li>• Loss of physical ability</li> <li>• Loss of self confidence</li> <li>• Loss of identity</li> <li>• Loss of control</li> <li>• Loss of innocence</li> <li>• Gain control and acceptance</li> </ul>	} <b>Loss vs. Gain</b> }	} <b>Transformation</b> }
<ul style="list-style-type: none"> <li>• Connections to mother</li> <li>• Disconnection from friends</li> <li>• Misunderstood by community/society</li> </ul>	} <b>Support vs. Rejection</b> }	} <b>Social Functioning</b> }
<ul style="list-style-type: none"> <li>• Positive attitude</li> <li>• Realistic</li> <li>• Emotional</li> <li>• Empowerment</li> <li>• Self-awareness</li> <li>• Responsibility</li> </ul>	} <b>Survival, Pain and Pride</b> }	} <b>Emotional Well-Being and Physical Functioning</b> }
<ul style="list-style-type: none"> <li>• Lack of sensitivity</li> <li>• Too little information</li> <li>• Frustration</li> <li>• Trivialization</li> <li>• Ignored</li> <li>• Disregarded</li> </ul>	} <b>Physician-Patient Relationship</b> }	} <b>Relationship with the Medical Community</b> }

## Patient – Physician Relationship

Skuladottir and Halldorsdottir (2008) state that women view health professionals as potentially powerful people. Physicians can greatly influence women's experiences of demoralization. Negative encounters with the medical profession, caused by delayed diagnosis or a lack of support, can create a rift between patient and physician and result in a lack of confidence in the physician.

Kaitlyn did not experience a delay in diagnosis, and her gynaecologist was extremely thorough in preparing her for her first laparoscopic surgery. He provided her with exact information relating to what the procedure entailed and showed her photographs taken in theatre so that she was able to prepare herself. This allowed her to build a strong relationship of trust with her physician. However, she acknowledges that at that point she still did not fully grasp the extent of the disease and the ways in which it would affect her life.

Kaitlyn currently feels that her physician lacks sensitivity and fails to fully explain treatment options, preferring to dictate the best form of treatment instead of entering into a discussion concerning the possible side effects. She expressed frustration that the doctor fails to provide her with sufficient information, leaving her to source the information for herself.

*I think the doctors are maybe so used to telling people that this is it, they don't know actually how to explain it to you properly. I read about the side effects and everything in the little leaflet that came with my injection. My doctor never said one word to me about it. They might – don't know, can I say get bored of telling people, but I think they need to actually be more aware of that they're talking to a new patient each time and they've actually got to give you all the details. They can't just assume that you're going to go and read about it or you already know what's going on because you don't.*

This lack of communication has created a rift in the relationship, and has led to Kaitlyn feeling ignored, disregarded and unable to control the situation. Kaitlyn's physician initially suggested that menopause should be induced to slow down the

progress of endometriosis. Lack of shared information about this course of action led to feelings of fear, anticipation and shock. She felt a total lack of control and unnecessary stress at the thought of coping with this treatment. The doctor ultimately altered his decision and placed her on the hormonal injection, Nur-Isterate, instead but again did not discuss the implications and side effects with Kaitlyn.

*He'll go, "Fine, go off the injections. You'll go back on this. You can't have that" and that's it. It's not – you know, we don't try and sit there and discuss like other options or another plan or whatever which I think is wrong. I think they should put their best effort in for each patient because each patient has their own feelings, own thoughts and that. So I think that they – they're wrong in just trying to get you in and out as fast as possible.*

Kaitlyn is still very young but her diagnosis of endometriosis has forced her to consider issues such as fertility and storing of eggs, issues her age mates do not have to address. Kaitlyn stated that she had raised these issues during a recent consultation with her doctor. The physician disregarded these concerns and trivialized her disease:

*I thought about the storing of eggs and we asked the gynae and he said "No, it's not necessary". But I still think about it more often like "Why not", just in case, you know.*

The doctor has failed to address the potential psychological impact of being unable to conceive in the future and has failed to listen to the needs and concerns of his patient. A referral to a fertility specialist would have enabled Kaitlyn to have her fertility assessed and find out about her various options. Kaitlyn's story speaks to a reluctance and arrogance on the doctor's part and an assumption that he can somehow guarantee her fertility without having conducted any fertility tests. This attitude may be due to a lack of knowledge and education in terms of current endometriosis research. It could also stem from a simple disregard of the long-term consequences of endometriosis.

Experiences such as these cause women to feel that physicians dictate to them and fail to treat them holistically. As a result of such treatment research (Skuladottir & Halldorsdottir, 2008) has found that women are increasingly turning to the internet

and interactions with support groups and “epistemological communities” for guidance and recommendations. These alternative sources of support and information allow women to feel empowered and take control over their bodies and treatment plans.

### **Survival, Pain and Pride**

The conversation with Kaitlyn made it evident that she has a survivor mentality. She approaches her life with endometriosis in a positive manner, something that she attributes to the example of her mother who has overcome both endometriosis and breast cancer. Although she endeavours to remain positive, she is realistic about her disease and experiences the emotional roller coaster that often accompanies a chronic illness.

*It (endometriosis) is more and more in the back of my mind. I don't think about it all the time, but you'll have your days when you do think, you know, why did this happen, you know, why do you have to have it, when you're so young as well.*

*And I think you could say maybe like even a mild depression because I'm not that kind of person to have mood swings and I'm normally a very happy person, But since being on that (the Nur-Isterate injections), some days you wake up and you actually just don't want to get through the day.*

*I have mood swings definitely and you could say more emotional. I've always been a sensitive person, but I think it's a lot more now since my hormones are doing all funny things.*

Kaitlyn displays high levels of maturity in dealing with endometriosis. She empowers herself by gaining knowledge on her disease and does not wallow in self-pity. She aims to live her life fully and to ensure that she finds meaning and enjoyment on a daily basis. Many women experience anger in relation to chronic disease. This anger is then internalised and leads to depression and isolation. In contrast, Kaitlyn chooses to be self-aware and acknowledges that she did not cause this disease. In this way Kaitlyn is able to live with endometriosis.



*I think this has happened to me and you've got to deal with it. I think maybe in the future I could feel angry when it does come to having children if it doesn't happen, but now I just think "Ag, it's happened, you know. We've got to deal with it and help me out however you can."*

*You just go day-to-day and just realise that it's happened to you for a reason and you've got to deal with it.*

*Some days are more difficult than others. I have to get on the medication and we have to try to keep it under control and that's just how it goes from day to day.*

Kaitlyn accepts responsibility for her awareness of her body and communicates openly with those around her, including with her physician.

### **Loss versus Gain**

A diagnosis with endometriosis is connected to loss of health and physical abilities. Physical tasks that are often taken for granted can be extremely difficult to carry out for women who are symptomatic. For women who are currently asymptomatic, there may not be a current loss of physical abilities but concerns remain over possible future losses. Kaitlyn has experienced a sense of loss in various areas of her life. Through the process of dealing with her losses she has gained control, insight and acceptance.

#### **Loss of physical activity.**

Chronic illness is often associated with physical disability. Although some symptoms may be perceived as under control, over time new symptoms or complications may emerge as the disease progresses.

The loss of physical activity was evident in Kaitlyn's story.

*I was a big swimmer at school. So I enjoyed swimming and that but when I was having my period it was actually like I couldn't do it. And I sometimes actually wish I could've like stayed at home on those days because I was in so much pain and nothing helped for it at all. You could lie in a hot bath, rub all creams and everything on, nothing would help it.*

*Obviously I had to take time off work last year (due to her operation).*

Kaitlyn finds the pain to be particularly debilitating. She said:

*Some days I'll get like shooting pains, it feels like going through my ovaries. Um, I think I battled more with the backache than the actual stomach cramps and that. Because I am a beautician some days are harder than others.*

### **Loss of self-confidence and identity.**

Physical changes resulting from treatment, such as gaining weight or experiencing menopausal symptoms, are frequently associated with fear. Although it is possible to argue that these side effects are not particularly severe they have a large impact on a woman's self-esteem and self-confidence, and may lead to changes in identity. These bodily changes are often perceived as losses.

Kaitlyn was clearly distressed by the changes in her body due to the hormonal treatments. These physical changes over which she has no control led to self-consciousness and impacted the way she viewed herself, particularly as she works in the beauty industry.

*I've always battled with weight. I've never been a skinny person, but I've even gone on diets now since I've been on the injection to try and lose the weight, because it's definitely affecting me. And my skin, most definitely because I'm not a person that has bad skin and now you're walking around with this skin that looks like mine. I definitely lack self-confidence and because I'm in the beauty industry, you're walking around with a bad skin that doesn't promote yourself very well.*

Kaitlyn did not feel that the hormonal injections warranted the physical and emotional changes she was experiencing and opted to consult with the physician in order to change her treatment plan.

Kaitlyn seems to have fought back in spite of these losses. She is defiant and protects what is meaningful to her: her self-image, identity and way of life. She is determined to keep her identity and to remain a driven, successful woman who is in control.

### **Loss of control.**

The diagnosis of endometriosis often brings with it uncertainty and feelings of loss of control (Weinstein, 1992). Kaitlyn raised concerns over the possibility of not being able to have children in the future, a possibility which she finds very distressing. She said:

*I wonder if it is going to happen and it plays on your mind. You know, are you going to be lucky or are you going to battle? I mean it's okay, I'm still only 21 but I mean in a few years time I could be at that stage of wanting to have children. And I think its going to be quite a stressful thing to find out yeah, am I going to fall pregnant or no, am I going to have a battle with it. So I think, it plays on my mind a lot.*

### **Loss of innocence.**

Most women assume that having children is a biological right and that the decision of when to have a child is in their control (Salzer, 1991). The generally accepted belief is that endometriosis is rare in teenagers and young women (Wood, 2010). However, as Kaitlyn discovered, this is a myth and there is no age restriction on endometriosis. At a very young age, Kaitlyn was confronted with a disease that has the potential to rob her of her fertility and this has forced her to face issues surrounding her body and mind that a teenager would not normally be expected to address.

*So I went for it (the first laparoscopic surgery) and he (the doctor) said I definitely had it. He said it was extremely bad for a girl my age. After the second operation the doctor said, "No, it's eating holes everywhere. You're bordering on infertile", it was quite a shock because I don't think I expected that. I definitely want the option of having children. You think at the back of your mind maybe you won't be able to (have children) and then you've got to find somebody who will be okay with, you know, not having children if they did want.*

Having to face the serious nature of this disease deprived Kaitlyn of her innocence, forcing her to think about her future in more concrete terms than most teenagers. It also influences the way in which she enters relationships and interacts within her social circle. She often finds that she has more serious concerns than most of her friends. This has led to emotional isolation and she has relied on her family, her mother in particular, for support as people her own age are unable to relate to her problem. However, she has been determined to maintain her identity and individual way of life.

### **Gaining control, insight and acceptance.**

In spite of these losses, Kaitlyn is able to reflect on the experience. She empowers herself by creating a sense of control and purpose. Endometriosis has allowed Kaitlyn to see the positive aspects of her life, and to live each moment to its fullest. She said:

*You must just go day to day and realise it's happened to you for a reason and you've just got to deal with that.*

*Um if they're (potential partners) going to get scared off by it (endometriosis), well then that's their problem. As far as I'm concerned it's something that comes with the package. If you've got me you've got to deal with it.*

## Support versus Rejection

A diagnosis of endometriosis, as with any other chronic disease, brings with it a need to connect to family, other sufferers and professionals. These connections help sufferers to develop new identities and gain a sense of control over the disease. However, sufferers also often experience feelings of disconnection from others.

The connection with her mother seems to have made Kaitlyn feel safe.

*I definitely think Mom has been supportive because she know what its like.*

Kaitlyn expressed a need to connect with other sufferers, particularly younger women. This need for connection relates to Kaitlyn's desire to share the responsibility of suffering and to gain the sense of community. However, this process has been difficult and to date unsuccessful. The lack of support groups has left Kaitlyn feeling isolated.

*I don't know anybody else like my age who has endometriosis. So it would be nice to talk to somebody else like around my own age.*

*I think so maybe to get someone else's – well, like opinion as well and speak to somebody different with – that can give you maybe a little bit more – not information but a little bit more help with the whole idea.*

Kaitlyn has not been able to connect with her friends in terms of her endometriosis. This is due to their inability to relate to her disease, and their lack of knowledge concerning endometriosis. This disconnection has led to further isolation. As Kaitlyn put it:

*Your friends, you'll tell them and they don't – I don't think they realise its such a big thing. I don't think they understand. It's fine, you know, being able to talk to Mom and all of that, but also nice to talk to a friend every now and again, and they don't actually understand what – what its like.*

*You know, friends at that age they don't really understand it either, so it's "Ag, you know what, it's just normal period pain. Get over it", but actually its not. It's not like that. It's way worse from what they were going through.*

These statements are evidence that Kaitlyn is aware of the lack of information available to women and the many societal myths related to 'female problems'. Kaitlyn has responded by creating her own network of support while remaining a private person.

Kaitlyn's story contains four global themes, namely: Social functioning, transformation, emotional and physical well-being and the relationship with the medical community.

### **Global Theme: Social Functioning**

Kaitlyn has struggled with belonging and acceptance, mainly as a result of being diagnosed at such a young age. Her social circle is unable to understand or empathize with her situation. The theme of social functioning refers to the process of involvement with others and participation in interpersonal exchange. Within the context of endometriosis, Kaitlyn has gained a sense of acceptance through her relationship with her mother, and has used her mother's example to engage with other sufferers.

### **Global Theme: Transformation**

Transformation suggests a change in nature, form, appearance or character. Kaitlyn's story is rich in descriptions of the ways in which endometriosis has influenced her life. For Kaitlyn endometriosis has led to the loss of her innocence, loss of control and loss of physical activity. However, these losses have contributed to her personal growth and self-acceptance. Kaitlyn has re-imagined her future and adapted her identity to include endometriosis.

**Global Theme: Emotional and Physical Well-Being**

Conservation is the process of preserving the status quo and creating stability within a context. Kaitlyn has been empowered by her mother's strength, which has allowed her to face the reality of endometriosis in a positive manner. Furthermore, her personal strength and abilities have allowed Kaitlyn to integrate endometriosis into her life, rather than being overwhelmed or consumed by it. She has been able to re-imagine her identity and attach her self-worth to factors greater than her disease.

**Global Theme: Relationship with the Medical Community**

Although Kaitlyn has established a relationship of trust with her doctor, she also experiences frustration with the lack of available knowledge from the medical community. Kaitlyn has often relied on her mother's experiential knowledge of endometriosis when doctors have trivialized or disregarded the side effects she experiences.

**Phillippa's Story****Background Information**

At the outset of this research project I made use of an endometriosis support group on a social network to obtain participants. I already knew Phillippa as we had attended school together. As a friend on my social network site Phillippa saw my post and offered to be part of the study. She was eager to discuss her experiences and struggles. I sent Phillippa my introductory letter and explained to her that her experiences would form part of my research project and that the interview would be recorded. Phillippa agreed to meet with me.

Phillippa is 34 years old and is married to Martin. They live in Middleburg, where she is self-employed.

Phillippa's struggle with endometriosis began when she was a teenager. She experienced heavy bleeding for extended periods of time and suffered severe pain. At

the time the doctors advised her that this was normal and suggested that she would simply outgrow it. When she was 23 years old she had her first laparoscopy and was diagnosed with endometriosis. Over the next three years she underwent operations approximately every three months to remove new growths. In total, Phillipa has had approximately 25 laparoscopic surgeries, often combined with the use of various hormonal treatments. Her continued absence from work resulted in her company sending her for evaluation by a local psychiatrist, who misdiagnosed her with bipolar disorder. This led to her being admitted twice to a local mental hospital, where doctors attempted to treat her. When these treatments failed the doctors recommended and performed a hysterectomy; Phillipa was only 27 years old at the time.

Phillippa does not live in Johannesburg and the interview was therefore conducted at her sister's residence in Edenvale on a weekend when she came to visit. Her sister, Jessica, also took part in the interview as Phillipa required the additional support and is unable to remember some details of her treatment as a result of the high dosages of medication that she was on at times. Both Jessica and Phillipa were welcoming and forthcoming during our conversation.

Throughout our conversation, it was clear that Phillipa was consciously and continuously aware of her own pain, both physically and emotionally. Telling her story was a very emotional experience for Phillipa, and she was extremely nervous when the interview began. At times I spoke to Jessica in order to give Phillipa a chance to regain her composure.



Table 4.5. Thematic network for Phillippa

<b>Basic Themes</b>	<b>Organising Themes</b>	<b>Global Themes</b>
<ul style="list-style-type: none"> <li>• Loss of a dream</li> <li>• Loss of physical ability</li> <li>• Loss of identity</li> <li>• Loss of financial stability</li> <li>• Gain control and meaning</li> </ul>	<b>Loss vs. Gain</b>	<b>Transformation</b>
<ul style="list-style-type: none"> <li>• Depression</li> <li>• Suicide</li> <li>• Work</li> <li>• Pain</li> <li>• Lack of control</li> <li>• Lack of self-esteem</li> </ul>	<b>Quality of Life</b>	<b>Social Functioning</b>
<ul style="list-style-type: none"> <li>• Peace</li> <li>• Awareness</li> <li>• Responsibility</li> <li>• Inability to accept aspects of disease</li> </ul>	<b>Acceptance vs. Rejection</b>	
<ul style="list-style-type: none"> <li>• Support network</li> <li>• Guidance</li> <li>• Disconnection caused by emotional strain</li> <li>• Destructive behaviour</li> <li>• Sadness</li> <li>• Inability to accept</li> </ul>	<b>Connection vs. Disconnection</b>	
<ul style="list-style-type: none"> <li>• Breakdown of trust</li> <li>• Lack of communication</li> <li>• Marginalized</li> <li>• Labelled</li> <li>• “Expert” knowledge</li> <li>• Frustration</li> <li>• Insufficient preparation</li> <li>• Transparency</li> <li>• Blame</li> <li>• Guidance</li> </ul>	<b>Physician-Patient Relationship</b>	

## Quality of Life

Endometriosis has affected all aspects of Phillippa's life and has reduced her quality of life and resulted in feelings of depression and even thoughts of suicide. She describes this as follows:

*I used to miss work because I was in a lot of pain most of the time. I think in three years I missed over a hundred days of work each year. I couldn't walk some days. I used to love going to gym. Eventually I couldn't – I couldn't exercise at all anymore, it was too sore. I'd say some days I couldn't drive my car or anything.*

*I was living with permanent plans to kill myself.*

Phillippa was unable to maintain her way of life and her years of intense treatment frequently meant that she was unable to make her own choices. She said:

*...They started investigating me for faking illness at work. I was sent to a psychiatrist and I had to undergo a whole lot of evaluations and tests to see if they were going to dismiss me or board me for whichever reason, for medical reasons.*

*I spent quite a while in and out of psychiatric hospitals. Every three months they were changing my medication, but eventually I seemed to get a little bit better.*

*Then one day at work they just came and fetched me from my desk and escorted me from the premises and I was still not allowed to put foot on – on the premises because I'm considered a suicide risk for the company.*

Glazer and Cooper (1988, p. 33) state that “one's self esteem is determined not only by external or societal reinforcements and cues, but also by internal cues that we perceive in our bodies. A healthy, well functioning body enhances our self-esteem”

(p.33). Phillipa has experienced years of suffering, her quality of life has been diminished and her inability to have children threatens her self-worth and self-esteem.

*The pain takes away your whole quality of life. You can't enjoy anything anymore because you're constantly hurting. Your body gets exhausted and then you're too tired to perform properly in any aspect of your life. You get miserable when you feel horrible all the time.*

*I think in my head – it defines you as a woman. I've always felt that the – the purpose of a woman is to be a mother and um – and I think I've lost my sense of being a woman because the one purpose that God created me for I can't or I don't have. It's something that I really struggled with, is that I don't feel like a woman anymore. I feel like I've just got this hole, and it was a big reason why it took so long to get married because I felt like I had lost everything that makes me a reason for a man to have a wife. I felt like I had nothing to offer a man other than a smile.*

The medication Phillipa received resulted in her gaining an excessive amount of weight. This further injured her self-confidence. As a young woman Phillipa was always thin and active. This physical change was not congruent with the self she knew and recognised, leading her to question her identity.

*I was huge and it's disgusting. When you've always taken such incredibly good care of your body. And that's another thing that I did feel from the endometriosis, I was so angry with my body, it was like it betrayed me. There's a lot of inner anger that comes with that.*

Asked how she feels now, Phillipa replied:

*I know that's not the truth because that doesn't define who I am but it's taken me a long time to understand that.*

*I still feel self-conscious, like people talk about how big my bum is when I'm walking, you know, or how my stomach sticks out. I think there's still a lot of work that I'm going to be doing in the next year or two or three.*

## Acceptance versus Rejection

For many women, having to accept the diagnosis of endometriosis and its possible implications is a difficult task. However, acceptance helps women to return to their normal lives (Van Dyk, 2005).

Phillippa has not yet been able to make peace with her inability to have children.

*I don't know if I'll ever fully come to terms with it.*

Endometriosis demands that sufferers seek advice and treatment from medical experts. However, sufferers do not always agree with the advice and treatment plans offered by the experts. Phillippa's family were forced to watch her deteriorate and began to educate themselves concerning her condition, which led them to question the medical professionals. Jessica made the following comment:

*My mom is very anti-medications, so she was – she was constantly reading up and researching and a lot of the symptoms were very similar to what Phillippa was experiencing but she wasn't the classic case of a bipolar patient. Phillippa used to walk around with a cooler bag of medication that she had to take every single day. For us as a family we just refused to accept the fact that this was the situation. My mom scouted around and found a doctor in Edenvale and we took Phillippa to see him.*

Following a correct diagnosis of hormonal imbalance, Phillippa began the gruelling process of detoxification. Phillippa simply stopped taking all her medication and it has taken her more than two and a half years to recover from the effects of her medication. Phillippa experienced major side effects from the medication, including organ damage and memory loss. However, she has begun to accept responsibility for the lost time and is starting to look forward to the future. Phillippa is learning to appreciate the here and now and this has helped her to accept the past and begin to accept the possibility of a future where she is not controlled by her disease.

*But it's exciting and I must say that I'm enjoying being alive now. It was hard to go through ... but I appreciate every beautiful moment of being alive now. Every month I see improvements and that's – it does encourage me. I still have difficulty understanding things. I'm very slow to um grasp the concept. That's frustrating because I always had a pretty excellent memory and I never struggled to understand even abstract concepts but now very simple things confuse me. But as I say, even that's improving each month.*

Salzer (1991, p. 307) writes “whatever your particular ending turns out to be, you can be assured there is life after infertility, and a very happy one at that!”

### **Connection versus Disconnection**

Connections and relationships help sufferers find support and gain a sense of control over their illness. Phillippa's family provided her with a support network that helped her to overcome her suicidal thoughts. Jessica said:

*We had a period of about five or six years where every single day it was routine for one of the children at a certain time of the day to phone Phillippa and tell her how fantastic she was and how special she was. I mean there were a couple of times where she actually wrote letters to the family about, you know, I love you so much but this is the end. And then that one phone call would be enough to actually swing her back and actually get her back on track again for another couple of days.*

Her husband has also been a constant source of support and guidance. Jessica described their relationship to me:

*Martin is the most incredible man. He's everything I could've wished for my sister. He absolutely dotes on her. He loves her. He just showers her with so much love and support and guidance. I think he diverted the energy that he knew that he could've put into a child into Phillippa, into their love and their nurturing.*

However, endometriosis has also damaged some of her relationships and Phillippa is currently disconnected from her younger sister. Phillippa described the change in her relationship with her sister:

*It destroyed my relationship with my little sister. We were always – it always felt like we were two halves that together made one body. We were able to talk to each other without saying one word. Through this little journey that I walked, she wrote me off pretty much. I became too much of an emotional burden to her. She couldn't carry on dealing with my crap. It was draining her too much.*

During her treatment for endometriosis Phillippa became severely depressed and began to disconnect from her own body and the experience of the disease in order to cope. She engaged in self-destructive behaviour, which she explained to me as follows:

*I started drinking very heavily to try and sedate myself even more. I wasn't coping and I just turned to alcohol. I think in a way I was also hope that it would kill me or that I'd have an accident or something like that. For eight years I was drunk. I wasn't sleeping at night. I used to go out and drink myself into a stupor. And I became very promiscuous. This sounds really thick to say, I was trying to get AIDS so that I didn't have to kill myself. It was like a slow way of suicide.*

Phillippa also expressed feelings of sadness with regards to other women who are able to have children. This sadness impacts on her ability to interact in society and she feels unable to share other's joy in relation to having children. The depth of her sense of loss is tangible.

*Like my best friend told me a while ago that she was pregnant, I couldn't congratulate her because I just – I was devastated. I can't go to stork parties for my friends and when their child does come, they know that they're going to have to excuse me for the first hour because as soon as I see the kid or baby – I just break down because, it is still my biggest desire in life.*

Phillippa has an extremely supportive and understanding husband. However, at times she feels that she does not deserve him and experiences guilt over the fact that she is unable to perform the roles that society prescribes for a wife.

*I don't know if I can do this to Martin. I don't know if I can let him sit with a wife that is too tired to wash herself, that is too tired to make food. And I do feel tired. Some days I'm overwhelmed by reality and then it's difficult to imagine a future because I feel like a burden, like an oxygen stealer. But most days I'm feeling very optimistic.*

## **Loss versus Gain**

### **Loss of a dream.**

Phillippa has always dreamed of having children. Like most women, Phillippa believed that having children would be possible. This dream was shattered when she underwent a hysterectomy. The situation is exacerbated by the fact that the treatment protocol was so dramatic and she does not feel that she was fully informed or in the right frame of mind to consent to such a life altering decision. According to Phillippa:

*I was so drugged that I never fully understood what was happening to me. That's very hard for me because, you know, when you're growing up you've got dreams of what you want to be when you're older and you want to be a lawyer or a doctor and, all I ever wanted to be was a wife and a mother. That was my dream. I don't know if I'll ever come to terms with it.*

### **Loss of physical ability.**

Endometriosis is frequently associated with chronic pain. Phillippa has experienced this pain since her teenage years. She describes living with this pain:

*I've had about two weeks of almost no pain. You know, it's just my stomach hurts all the time. It's very difficult to explain. I'm just in pain constantly but*

*internally. But as I say, the periods of less pain are getting longer and more frequent which is quite fabulous.*

Jessica stated that Phillipa still experiences bad days and feels defeated and depressed at points, particularly on days when her body aches so badly that she is unable to get out of bed. Phillipa has suffered organ damage as a result of some of the medications that she has used in the past. During the detoxification process she became very ill and had to be hospitalised.

*I literally vomited for 14 months. As a result of the constant vomiting the immune system got very weak because I wasn't getting any nutrients. I used to go for drips to rehydrated.*

Phillippa has come to terms with the fact that her body is not as strong as it once was, and her identity has adapted to accept this change and to focus on the future.

*Um, I've slowly been trying to just get my body stronger again and in the next few months I want to start exercising again. I don't think I'm strong enough yet for that. My muscles are very weak still because I was pretty much bed ridden for about 18 months and I think the muscles got very lazy.*

### **Loss of identity.**

Phillippa had always dreamt of being a mother and a wife. Endometriosis and resulting hysterectomy have taken that dream from her. This is a loss that she has not yet fully accepted and she feels that she may never quite come to terms with this.

*All I ever wanted was to be a wife and a mother. That was my dream. It took away everything, or it feels like it took away everything that ever mattered to me.*

Phillippa has had to re-imagine her life. Before meeting her husband she was involved in a number of relationships that ended because she was unable to have children. The



ending of these relationships further perpetuated her loss of identity, as she felt judged and worthless. She saw herself as ‘damaged goods’.

Phillippa’s self-esteem and identity were also brought into question when she gained excessive amounts of weight due to the medications she was taking. She was no longer the healthy, thin and independent woman that she was before and this created a loss of coherence between her mind and body.

*My mind and body haven’t connected yet and I still feel self-conscious. So it’s just been taking one area of my life at a time and trying to get that okay and then move onto the next one and then work on that one.*

### **Loss of financial stability.**

Endometriosis has a high cost – not only emotionally but also financially. Chronic pain results in inability to function adequately in the work environment and women suffering from endometriosis frequently have to take time off to recover from treatments. Phillippa has first hand experience of it as she was dismissed from her job due to her high levels of absenteeism. However, this loss of income did not result in a lessening of medical bills, resulting in excessive levels of stress. Phillippa discussed this further:

*One of the big implications of endometriosis was the financial aspect of it. It absolutely destroyed me financially. I’m still paying my gynaecologist off from 2005. I think the medical bills since being diagnosed with endometriosis to now with just the treatment and the medication associated with that has happened from there, is hitting around R900 000.00 now. It left me pretty much with no possessions. I was off disability and everything and I wasn’t getting any income at all, and at that stage I – that was when I moved back to Middleburg. Then I was cleaning houses to earn month and tutoring kids to earn month and running errands for people ... just so that I could pay rent. I didn’t have enough money for luxuries like food. I think in three months I didn’t cook a meal because I didn’t have anything to cook for myself. I was living pretty much off Pro-Vitas.*

This financial burden has had long-term effects on Phillippa. She is still facing legal action and is unable to receive any credit. All the money she currently earns is used to settle outstanding bills and thus directly influences her quality of life. However, she feels confident that she is nearing the end of this phase. In this regard her husband has been able to offer her financial support, thus alleviating some of this stress.

### **Gain control and meaning.**

The support and love of her family and husband have helped Phillippa to regain a sense of control in her life. She tries to remain positive about the future and tries to focus on gaining her strength and moving on with her life despite the tribulations she has faced.

*I feel like my body is going to get strong again and it is healing and – you know- what's come out of it – out of this is beautiful and I'm blessed and I've got so much to be grateful for. I feel a lot of hope. My mind's also getting better, um my memory is coming back.*

### **Patient – Physician Conflict**

Medical professionals should provide sufferers with support and patients should be able to trust the doctor-patient relationship. Unfortunately, Phillippa's story highlights how lack of physician communication and support can lead to feelings of isolation and desperation.

Like most women, Phillippa turned to a physician in the hopes of gaining knowledge about her condition and improving her health. Instead, she was labelled and marginalized.

*Within about 10 minutes of being in a consulting room she (the doctor) said I was bipolar and I was admitted to Denmar where I spent two months the first episode.*

*At one stage we went to go and see Phillipa in Denmar the first time they'd admitted her and they put her onto a whole lot of medication – her system was so sensitive that she couldn't even handle the children's dosages because even that was spacing her out so badly. And they were – I mean they used her as a guinea pig.*

Society believes that doctors hold expert knowledge. Phillipa's family proved that it is possible for laypeople to become experts on disease. They questioned her treatment and insisted on second opinions. Unfortunately, as is often the case, the doctors did not feel that the family had the right to question their decisions. Instead, they insisted that Phillipa herself had to raise queries regarding her treatment. Jessica shared this with me:

*And they called us in that evening and they said to us “No, you know, we're going to have a session and it's a counselling session”. They said they couldn't listen to anything we've got to say because it's got to come from Phillipa. And we were like “But she's so spaced out she can't even tell you anything”.*

The frustration with the doctors did not end there. Both Phillipa and her sister stated that the potential side effects of many of the drugs and treatments were never discussed with them. Phillipa was also never referred to a psychologist or counsellor. The physicians simply dictated treatment plans to Phillipa without providing her with alternatives or preparing her for the implications of the treatment.

*When Phillipa phoned us to tell us they had told her that she's got to have a hysterectomy, there'd been no consultations about alternatives. It was a case of “Oh well, we've taken out so many growths already, there's no hope, we're just going to remove it.”*

Phillippa indicated that she wished that the doctors had been more transparent. She would have preferred to build a relationship with the medical professionals based on trust and knowledge sharing. Furthermore, she expressed the hope that doctors will

begin to treat women more holistically and acknowledge the gaps in their own knowledge.

*I wish the doctors had just explained more. They just tell you, “Okay, you can go and read up on it on the Internet”, or “Here’s a little booklet’. When they start all sorts of drastic treatments and they don’t explain it to you what can you expect and all of a sudden your body starts going through all these changes and you don’t understand it and you think it’s something wrong with you. You start believing that there is something wrong with you and that you are crazy and that you are a lunatic and psychotic and ... not realising that is – it’s part and parcel of what they’re putting into you.*

*I’ve come across doctors themselves I think don’t even think about the side effects. They think that the drug will help the endometriosis and that’s where their job ends. And I think possibly they don’t understand the degree to which hormones rule a woman in a way.*

However, despite her misdiagnosis and incorrect treatment Phillipa is not bitter towards the medical fraternity. She has started working with the doctor who correctly diagnosed her hormonal imbalance. He has rebuilt her confidence in the medical profession, sharing his knowledge and guidance and most importantly, acknowledging her suffering so that she no longer feels isolated and blamed.

*He had a lengthy session with her and I think they were there for about an hour and a half. And they ran a whole lot of tests and they found that her female hormones were so below the radar that they were actually in the negative. And that’s when he helped her along.*

This experience highlights the importance of the professionals’ acknowledgement of suffering. Doctors need to be aware that women are the experts in relation to their own bodies; they know when something is wrong or does not feel right. These perceptions should not be ignored.

Phillippa’s story highlighted three global themes, namely: Social functioning, transformation and the relationship with the medical community.

**Global Theme: Social Functioning**

Phillippa's ability to function and participate in society has been severely affected by her experience with endometriosis. In addition to the physical side effects of the drugs, she suffers from memory loss and is traumatised by her inability to have children. This severely limits her interpersonal connections. Phillippa has begun to gain a sense of acceptance and control through her relationships with her husband and her family, who have provided a support network throughout her ordeal. She has begun to accept the changes that endometriosis has wrought in her life and is working on improving her quality of life by relying on those around her. Phillippa makes use of her insight and experiences to create a better understanding of herself, her life and her future.

**Global Theme: Transformation**

Phillippa's difficult past and experiences since diagnosis have had a substantial impact on the woman she is today. Phillippa describes endometriosis as crippling her financially, physically and emotionally. However, the experience of endometriosis and her relationship with her husband have allowed her to transform her life and to establish a new context for her future. Phillippa's life has been full of challenges, instability and setbacks. Nevertheless, she has adapted to these fluctuations and has begun the process of recreating her identity based on her experiences and her new reality. This has helped to foster an environment in which she feels she is able to move forward.

**Global Theme: Relationship with the Medical Community**

Phillippa has been extremely disempowered by the medical fraternity. She has previously been unable to preserve the status quo or build a relationship with her doctors. Phillippa's doctors dictated treatment options to her and did not discuss the serious repercussions of undergoing a hysterectomy. These doctors also mislabelled her as bipolar. This lack of communication has led to Phillippa experiencing severe anxiety and feelings of inferiority. The lack of support from the medical community

has led Phillippa to rely on her family to provide her with strength. Her family has helped her to create a stable reality and she has now increasingly been able to rely on herself.

### **Personal Reflections**

In my conversations with the participants I was struck by their strength and resilience. Although the disease challenged their identity and self-esteem they were able to re-invent themselves and make sense of their new identities. At times, the younger participants approach their disease with a naivety that allows them to look to the future without being disheartened. Most of the women had not really contemplated the psychological effects of endometriosis prior to our meeting. Instead, they told me their stories from a medical perspective and only then began to relate the psychological effects of their experiences.

I also noted that Charlene and Anne, who have already had children, have a very different experience of endometriosis to the other participants. Having completed a family seems to alleviate much of the stress and anxiety surrounding endometriosis. These participants seem to cope better with the symptoms of endometriosis than the women who still harbour concern over their futures and fertility.

Finally, the relationship between the participants and their doctors was a key factor in all the stories. Some of the participants had positive experiences, while others had negative experiences. Regardless of the nature of this interaction the patient-doctor relationship was instrumental in the way in which the participants coped with endometriosis. Supportive relationships allowed the women to share their suffering and feel acknowledged and positive about the future. On the other hand, negative interactions created a sense of isolation and desperation, adding to their already high levels of anxiety and anticipation.

### **Conclusion**

The themes identified in this chapter are not absolute and do not represent the experiences of all endometriosis sufferers. The themes developed through the

interaction between the participants in this study and the researcher. The subject matter in the interactions was often painful and holds personal significance for both the interviewer and interviewees. All the participants have individual life experiences that have shaped their relationship with endometriosis.

Pain and uncertainty were central concerns in the stories of all the participants. A lack of knowledge and the existence of various myths within society perpetuate an environment whereby women suffering from gynaecological diseases are marginalized.

Resolution involves the ability to make sense out of confusion, build bridges where relationships have been severed, accept a future that is different to what was expected and make peace with the self (Salzer, 1991). For the participants resolution is the final stage in their relationship to endometriosis and allows them to create balance in their lives and begin the re-invention of their lives and futures.

In the next chapter an integration of the identified themes is provided. A comparative analysis of the relevant literature and the identified themes is also provided.

## Chapter 5

### A COMPARATIVE ANALYSIS

#### The Combined Voices of the Participants and the Literature

##### Introduction

When conducting research it is of vital importance that the context, the social constructions of individuals, groups and problems, is taken into account. Emphasis must be placed on the formation of narratives with the appreciation that ours is a storied reality (Becvar & Becvar, 2006).

It is important to deconstruct and compare the participants' stories, as the self is not an isolated, autonomous creature but is constructed in relationship to others (Becvar & Becvar, 2006). The relationships that endometriosis sufferers develop with their doctors, partners and society lay the foundation for the relationship that they develop with themselves and their disease.

Endometriosis is a chronic disease and impacts all aspects of a woman's life (Taylor, 1991; Weinstein, 1992). Health psychology investigates the psychological reasons for health and illness (Taylor, 1991). A diagnosis of endometriosis is usually accompanied by a temporary phase when all life activities are disrupted. After this phase there will be intermittent periods of intense symptoms that require the sufferers to make changes in activities in order to manage their disease. Immediately following diagnosis many women experience a state of crisis, marked by physical, social and psychological disequilibrium (Taylor, 1991). Habitual ways of coping may no longer work and they may experience intense feelings of anxiety, disorganisation, fear, guilt and depression (Salzer, 1991). It is possible to see endometriosis as consisting of a series of crises that create never-ending stress, often culminating in infertility. These variables all combine to shape the way in which a woman reacts to her diagnosis and the way in which she tackles her future.

This study focused on the ways in which women deal with endometriosis and the impact it has on their lives. The study investigated the ways in which the participants



have successfully overcome their suffering and found meaning. In this chapter the themes that emerged from the participants' stories are discussed in relation to the relevant literature. This chapter is not an attempt to substantiate the findings of the study, but instead aims to include many different voices concerning the same subject. Each participant's story is unique and represents her own particular perceptions, cognitions, emotions and history and the way in which these have contributed to her worldview and her reality. When reference is made to a particular participant's life this is for the purpose of illustration only and does not necessarily represent the experience of the other participants.

Table 5.1 presents the organising and global themes that emerged from the analysis of the interviews. There were similarities and differences between the participants' experiences. Although some of the themes were given different names in the narratives of different participants the researcher felt that these themes were related and they have therefore been presented together.

*Table 5.1.* Summary of organising and global themes across the five participants

<b>Organising Themes</b>	<b>Global Themes</b>
<ul style="list-style-type: none"> <li>• Generational legacy of endometriosis</li> <li>• Fragmentation of mind &amp; body</li> <li>• Identity transformation</li> <li>• Identity through self-awareness</li> <li>• Loss vs. gain</li> </ul>	} <b>Transformation</b>
<ul style="list-style-type: none"> <li>• Survival, pain &amp; pride</li> <li>• Sexual dysfunction</li> <li>• Denial by putting other first</li> <li>• Fear</li> </ul>	} <b>Emotional well-being &amp; Physical functioning</b>
<ul style="list-style-type: none"> <li>• Intellectualizing vs. understanding</li> <li>• Relational issues</li> <li>• Support vs. rejection</li> <li>• Quality of life</li> <li>• Acceptance vs. rejection</li> <li>• Connection vs. disconnection</li> <li>• Social interactions</li> <li>• Relational patterns</li> <li>• Infertility as stigma</li> <li>• Frustration inciting healing</li> </ul>	} <b>Social functioning</b>
<ul style="list-style-type: none"> <li>• Physician-patient conflict</li> <li>• Physician-patient relationship</li> </ul>	} <b>Relationship with the medical community</b>

## **Relationship with the Medical Community**

Health professionals exert a powerful influence over the women they treat. This influence can serve to empower women and keep them motivated or it can disempower them and contribute towards their demoralization (Skuladottir & Halldorsdottir, 2008). The relationship between patient and physician is thus exceedingly important. Phillippa experienced a tremendously demoralizing downward spiral as a result of misdiagnosis and years of inappropriate treatment. However, her meeting with an empowering health professional started her on a journey towards empowerment. She began to consider her own well-being and regained a sense of purpose, slowly gaining confidence in her future and the belief that she would recover.

Endometriosis is a chronic and progressive disease and the relationship between physician and patient is frequently long-lasting, leading to patients investing considerable amounts of time and emotion. The doctor is usually seen as the expert who provides guidance and facilitates treatment and who should not be questioned. Unfortunately, some doctors exercise arrogance as well as authority and female patients frequently feel overwhelmed or intimidated by doctors. These patients are afraid of asking questions that may sound naïve or stupid.

When Estelle first contacted a doctor three years ago she was told that the pain she was experiencing was normal. Like so many other women Estelle accepted her doctor's explanation of her pain. However, she remained frustrated at the lack of a definitive diagnosis and sought help again a year later. Once again she was told that the pain was normal. It was only in the face of escalating pain that she decided to take responsibility for her own physical health and began to investigate further without the advice of a doctor. This breakdown of the physician-patient relationship left Estelle feeling anxious and despondent. She has since been able to connect with a new physician, but still feels intimidated and lacks the confidence to question his authority and recommendations.

Salzer (1991) highlights the importance of women being active in their own treatment. They need to learn to question, evaluate and discuss options with their

doctors. In order to successfully treat endometriosis doctor and patient need to work as a team. In order to achieve this goal women need to be empowered and need to acknowledge that they are the experts in their own lives. The relationship between physician and patient is most productive when mutual trust and consideration exist (Paterson, 2001).

Endometriosis and its treatments are mired in uncertainty and women often experience anger and frustration when dealing with doctors. This anger is sometimes misplaced and at times patients need to be able to step back and gain perspective on the situation. However, some doctors are simply not well informed about endometriosis and its treatments. At other times doctors allow their own judgements and values to shape their decisions regarding treatment plans (Weinstein, 1992). These doctors provoke reasonable anger in their patients as they directly impact on the patients' treatment and experience of endometriosis (Weinstein, 1992). Weinstein (1992) states that arrogance, ignorance and chauvinism continue to exist in medicine. Instead of continuing in counterproductive relationships women need to accept control and actively make choices regarding their treatment and choice of physicians. Phillipa was directly impacted by a common medical misconception when she was told that her heavy and painful menstrual cycles were normal and that she would outgrow them. In a similar fashion after the birth of her first child Charlene was told that her endometriosis would improve. This was in fact not the case and she returned to her doctor when cysts began to redevelop. Estelle's doctor implied that the laparoscopic surgery would cure her endometriosis and that her concerns about her future fertility were unfounded.

Unfortunately, accounts of the medical mismanagement of endometriosis on both the physical and emotional levels are not uncommon (Salzer, 1991). Whelan (2007) explains that patients and physicians often experience conflict relating to signs and symptoms. Pain is usually a primary symptom of endometriosis, but the experience of pain is subjective and often does not correlate with observable medical observations. Physicians sometimes doubt the reality of the pain experience, leaving the patient frustrated and disheartened. In the stories told by Estelle and Phillipa the physicians failed to acknowledge their reported pain and the influence it had on their quality of life. Her experience of pain stopped Estelle from enjoying a fulfilling sex life with her

partner, while Phillippa's pain disrupted almost every aspect of her life including work, social and physical activity.

Some doctors are unaware or uncomfortable with the emotional impact of endometriosis and do not consider emotions when treating their patients. They may dismiss any emotional difficulties as unimportant or may trivialize the side effects of the treatments. Anne found that the hormonal treatments she was placed on caused excessive weight gain. She was not told of the possibility of this side effect prior to being placed on the treatment and when she raised the issue with her doctor his response was that: "Yes, it is a side effect, but it's something that you have to deal with". The doctor never considered the impact of the weight gain on her self-esteem or identity and never addressed the potential psychological damage that could be caused by this side effect.

According to Taylor (1991), people often judge the adequacy of their health care based on criteria that are irrelevant to the technical quality of the care. In return, medical professionals often misjudge a patient's ability to understand aspects of endometriosis and its treatment. In some cases, doctors resort to simplistic explanations or baby talk. This type of communication positions women as helpless children and creates a barrier to open dialogue and informed discussion. The doctor-patient relationship can also be impaired by the tendency that some doctors have of depersonalising their patients (Taylor, 1991). Doctors often use nonperson treatment at particularly stressful moments (such as during internal examinations) in order to keep the patient quiet. Nonperson treatment also provides physicians with emotional protection as it helps them avoid connecting with their patients. Taylor (1991) states that physicians prefer dealing with acute (as opposed to chronic) disease because chronic disease is often related to numerous uncertainties and poses questions about prognosis that doctors are not necessarily equipped to answer.

All five participants indicated that their doctors did not adequately prepare them for the diagnosis of endometriosis and the treatment regimes they would have to follow. Instead of entering into conversations the doctors provided limited information and dictated treatment plans without addressing potential side effects or implications. Estelle mentioned that even after her laparoscopy and follow-up appointments she did

not fully understand the causes of endometriosis or the steps she could take to improve her quality of life. Kaitlyn, Phillipa and Charlene all made use of additional sources to gather information. These sources included the Internet, pamphlets and connecting with other sufferers.

Some doctors perceive patients' attempts to participate in decisions as invasions of their professional territory (Paterson, 2001). The women in this study all stated that their participation in the planning of their treatment regimes was restricted to agreeing to comply with the prescribed regime. Most doctors fail to consider their patients' experiential insights. These insights could offer doctors a greater depth of understanding and provide the women with a source of power. Endometriosis sufferers often make use of experiential knowledge when making self-care decisions, even if these decisions contradict the advice of medical practitioners. Anne and Charlene both felt that the side effects of their treatments were too great and decided to stop these treatments without consulting their doctors. Instead, they found alternative treatment that did not impact as heavily on the functioning of their families.

The medical experts' representation of endometriosis often undermines the credibility of patient accounts. Endometriosis patients are often misrepresented in literature as nervous, irrational, controlling women who exaggerate their symptoms (Whelan, 2007). This delegitimises their experiences and forces them to seek support from endometriosis communities, often in the form of support groups. These epistemological communities empower women to challenge medical authority and to become knowledgeable about their disease. The Internet has become an important tool in self-education regarding endometriosis (Whelan, 2007).

The participants all acknowledged the need for social support amongst sufferers and expressed interest in joining a support group. However, they indicated that support groups for endometriosis were difficult to find and they received no assistance from their physicians in this regard. Kaitlyn's doctor did suggest that she join a support group, but was unable to provide her with any details or contacts. Phillipa had contact with a Johannesburg based support group, but this group specialises in fertility problems and is not focused exclusively on endometriosis.

Within the medical fraternity the treatment of endometriosis is almost always focused on pain or infertility (Denny, 2009). Women are rarely asked about the disease's impact on their ability to function or on their relationships. Denny (2009) found that the majority of endometriosis sufferers manage their symptoms through self-medication, dietary change, exercise or alternative treatments such as reflexology. Many of the hormonal treatments currently used for endometriosis have severe side effects that affect the appearance of the body. These side effects typically include weight gain and menopausal symptoms. Although women report suffering loss of self-esteem or reduced quality of life as a result of these side effects, most doctors believe that the side effects are relatively minor and justifiable in terms of disease management. This lack of sensitivity highlights the differences in the assessment of endometriosis by doctors and patients. If these differences are to be overcome then open communication between doctors and patients is vital.

The final concern raised by the participants involved the lack of shared knowledge. Doctors seem hesitant to share their expert knowledge with patients. All five participants reported that they were inadequately prepared for the side effects of the various treatments they received. In order to treat the cysts that she was developing Charlene was placed on continuous use of the contraceptive pill. She described herself as becoming a monster as a result of the hormonally induced mood swings. Kaitlyn's doctor placed her on hormonal injections that led to weight gain and skin problems. Phillippa's doctors made use of a variety of medications that have had long-term implications for her health. As a result of these treatments she now suffers from organ damage and memory loss. In all these stories the doctors were insensitive to the possible side effects and failed to prepare their patients for the impact of the treatments. Although the physicians believed that they were doing the best for their patients by treating the endometriosis they failed to consider their patients' perceptions of the treatments.

## **Transformation**

The global theme of transformation is composed of the organising themes labelled the generational legacy of endometriosis, loss versus gain and identity. Transformation describes the process of change, development and growth.

### **Generational Legacy of Endometriosis**

The environment an individual is raised and socialised in establishes their norms and realities. Our attitudes and expectancies about relationships are learned from our parents (Baron, Byrne, & Branscombe, 2006). These patterns of interactions are frequently brought into question as individuals mature.

Patriarchal society has resulted in a legacy of silence regarding ‘female problems’, which are considered taboo topics and are not discussed openly. In this environment it is not surprising that endometriosis sufferers frequently experience a lack of support and understanding from their family members (Taylor, 1991). This often results in sufferers being isolated as a result of loved ones’ misconceptions regarding the disease. These women often feel that their infertility is a disappointment to their families.

Charlene’s story clearly highlighted her family’s cultural reluctance to speak about gynaecological problems. Instead, she was simply barren and her interaction with her family failed to address her diagnosis and its effect on her life. This inability on the part of her family to name the disease implies that, in some way, her family feels she is responsible for her problem. Her family’s response has left Charlene feeling isolated and she has not received support from her family. Salzer (1991) states that women with fertility problems often blame their parents for a lack of sensitivity, but that this is frequently due to the women’s own high levels of anxiety and use of defence mechanisms. It is difficult for people to acknowledge the suffering of others when their personal pain is intense, and it is possible that Charlene’s parents are experiencing shock, anger and even guilt but are unable to express these feelings.



The theme of guilt was present in Charlene and Anne's stories. This guilt was associated with the hereditary nature of endometriosis. Anne's daughter suffers from stage III endometriosis and she struggles with the knowledge that she has passed this legacy to her daughter. Her guilt focuses on her daughter's quality of life, and she wonders whether her daughter will be able to have children or live a normal life without constant pain. Charlene's daughter is still very young, but Charlene is concerned about her daughter's future and the possibility that she will develop endometriosis. Their understanding of the effects of endometriosis and its treatment has resulted in these participants experiencing feelings of guilt and self-blame.

According to Weinstein (1992) women with endometriosis often feel guilty about the effects of the disease. These guilt feelings relate specifically to the loss of physical ability, the inability to meet responsibilities or the demands of society and the fact that others must watch them suffer or suffer with them.

### **Loss versus Gain**

The participants' stories reflected a theme of loss. They experienced or feared the loss of physical abilities, their dreams, control, identity and self-esteem. Most of the participants mourned their losses but were able to acknowledge gains in other areas of their lives.

The participants all experienced a loss or possible future loss of physical ability. Jones et al. (2004) state that endometriosis influences mobility and daily activities. Many women experience sleeping difficulties and have trouble walking, standing, sitting or exercising. Phillipa stated that she battles to sleep. Kaitlyn struggles to work because she is required to be on her feet all day. Both Phillipa and Kaitlyn had to stop exercising. This loss of physical functioning directly impacts on their performance in their various roles. Anne advised that on some days she is unable to continue with household activities, while Kaitlyn is sometimes unable to work. Estelle's pain is less severe on a daily basis and does not prevent her from engaging in normal activities. However, her pain has a direct impact on her ability to engage in a healthy sexual relationship with her partner, leading her to question her role in the relationship and as a woman.

Holtzman (2010) suggests that the loss of health or physical ability and the ramifications of this loss may present as a grief process similar to the grieving process described by Elisabeth Kubler Ross. Loss may thus be accompanied by feelings of denial and shock, anger, bargaining, guilt, depression and acceptance (Van Dyk, 2005). The participants experienced these emotions.

Estelle and Charlene experienced a sense of loss of control when they discovered that something was wrong with them. This feeling intensified for Estelle when she was actually diagnosed with endometriosis. Charlene felt a complete loss of control when she discovered that she was pregnant. On the other hand, Phillipa experienced a sense of relief when she was diagnosed because the diagnosis provided an explanation for the pain that she was experiencing. Estelle still experiences a sense of loss of control over her future. This is mainly due to the lack of information from her doctors and her own her sense of trepidation surrounding her relationship with her partner.

Endometriosis is an unpredictable and complex disease (Weinstein, 1992) that takes the form of a chronic illness. The uncertainty and unpredictability can be very stressful and can leave sufferers feeling out of control. This sense of being out of control was present in Estelle, Phillipa and Charlene's stories. This lack of control can impinge on various areas of the sufferer's life. The sufferer is faced with physical, emotional and social changes that she unable to predict (Holtzman, 2010). A certain level of loss of control was evident in the stories of all five participants.

The theme of loss of identity was prominent in all five stories. Phillipa was a health conscious athlete and independent woman who is struggling to redefine herself as less active and insecure. When Kaitlyn gained weight and battled with her skin, she struggled to reconcile her feelings about herself with her perception of herself. This was particularly challenging for her as she works in the beauty industry. Charlene felt powerless with regards to the mood swings and emotional turmoil caused by her treatments, and was unable to accept this change in her identity. Estelle has seen herself as an attractive, sexual woman who aimed to please her partner and she tried to maintain this identity through silence. However, her silence has failed her and she now battles to redefine herself in terms of her new sexual identity and limitations.

When weight gain challenged Anne's perception of herself she was determined to regain control and created a new identity in line with her current perception of herself.

Loss of identity is a central theme in the experience of endometriosis. Loss of identity is linked to infertility, victimization, relational changes and loss of physical abilities or the ability to work (Ballweg, 2004). The pervasive nature of endometriosis means that endometriosis sufferers often have to redefine their roles. Fitzpatrick (2002) notes that identity changes are experienced when the physical self is threatened. This is experienced as a loss of the core sense of self. Illness forces a person to realise how much of their identity is tied up with the potential loss of ability (Fitzpatrick, 2002). Endometriosis does not always present with physical symptoms that are visible to others and many women choose to keep their illness a secret in an effort to maintain their original identities.

Loss of a dream is a prevalent theme for women with endometriosis. Phillipa has always dreamt of being married with children. However, the disease ravaged her body and, following her hysterectomy, this dream is no longer a possibility for her. She is devastated by her inability to conceive and at times feels defective, damaged and inadequate. For Phillipa this loss of a dream led to the destruction of her confidence, self-esteem and feelings of worth. Phillipa has not yet come to terms with the loss of her dream of children, but her husband's love and reassurance that she is in fact a 'whole' person is helping her come to terms with her disappointment and loss. Through this support she is beginning to re-imagine the future. Charlene's initial diagnosis of endometriosis also resulted in the loss of a dream. She was suddenly faced with the possibility of life without children and was ostracized by her community. Estelle's dream is of a fulfilling sexual relationship with her partner, free of pain. After her first laparoscopic surgery, she felt that this dream was within her grasp and believed that she would be able to celebrate her sexuality. This dream was quelled when the pain returned and she realised that she may have to live with endometriosis and its impact for many years. This process has allowed Estelle to become more aware of her body's nuances and she is fighting to regain her sexual identity through this awareness.

For most women overcoming the loss of a dream involves accepting the loss, grieving the loss and then creating a new dream that allows them to move forward (Weinstein, 1992).

The process of knowledge gathering allowed the participants to gain control. They sought information from various sources, such as books, professional advice, the Internet and the experiences of other sufferers. Charlene read extensively about natural and alternative treatment options that would have less impact on her daily living. Estelle is still in the information-gathering phase and is trying to assimilate the information gathered from the professionals with her personal experiences. Talking to a friend who also suffers from endometriosis has made her aware that she is not alone in her diagnosis. Kaitlyn has made use of her mother's extensive knowledge of endometriosis and has also educated herself regarding the disease. Phillipa experiences memory lapses and is unable to remember periods in her life. Her family members have been instrumental in providing her with information about these times. Phillipa has made use of this new information and through combining it with self-education on recovery techniques she is in the process of regaining control of her life. Anne's story is slightly different to that of the other participants. She has now entered menopause and her disease has essentially entered remission. Anne no longer suffers the direct impact of endometriosis. This has helped her regain control over her life and body and is she is now in command of her own future.

Knowledge is often associated with power. Traditionally, within the medical fraternity the physician holds privileged knowledge and is in control of the patient-professional relationship (Becvar & Becvar, 2006). However, these women were able to gain control by acquiring knowledge about endometriosis. This knowledge empowers them to make informed choices and identify resources that will be effective agents of change (Van Dyk, 2005). The stories of the participants reflect the role of knowledge in their quests to gain control over their disease. Estelle indicated that if she knew more about her disease she would feel greater control as this would make her disease more predictable. She feels that if she can understand the origin and cause of the disease then she will be able to make changes and prevent it from progressing. Taylor (1991) states that exploring the cause of the illness helps patients to find meaning in their illness.

Anne has gained meaning from her experience with endometriosis. The insight she has gained is helping her daughter cope with endometriosis. This allows Anne to feel that her suffering was worthwhile as through it she is able to contribute to her daughter's well-being and future care. Charlene has also found meaning in her journey with endometriosis. Charlene has a daughter and this has helped her understand that the legacy of silence is destructive and isolating to individuals suffering from chronic diseases. She hopes to share her knowledge with others suffering from endometriosis and aims to educate her daughter so that silence is not transmitted to the next generation. Although Phillippa has not yet gained meaning from her suffering she is currently enjoying a new and positive attitude towards life. Taylor (1991) suggests that this might be attributable to her renewed sense of purpose as a wife. Phillippa is still coming to terms with the losses she has experienced as a result of endometriosis. Kaitlyn and Estelle are still young women and have not yet found meaning in their experience. Instead, they are currently in the process of understanding the disease and its possible ramifications, and adapting to the changes that endometriosis has wrought in their lives.

The participants have all transformed themselves as a result of the diagnosis and impact of endometriosis. The participants have all felt isolated, hurt or insecure at times and yet describe personal growth as a result of their experiences. For these participants their experiences of pain, losses and hardships have been learning experiences that have helped to make them stronger women. For Charlene, the experience of transformation has enabled her to change family patterns. Kaitlyn and Phillippa have been able to regain control over their lives and futures. Anne has gained awareness and now re-imagines her future as her daughter's mentor. Endometriosis has required that these women are flexible in their roles and that they adapt to the new situation. In doing so they have been able to separate the disease from the 'authentic self'.

### **Social Functioning**

Endometriosis represents an assault on a woman's body and sense of identity. A loss of confidence in her body frequently leads to a loss of confidence in social interaction

(Bury, 1991). Bury (1991) described this as a biographical disruption, a phrase which takes into account both the context and the meaning of illness. Meaning is a function of the consequences for the individual as well as the significance that the individual attaches to the diagnosis of endometriosis. In this way endometriosis carries unique connotations and imagery for each individual sufferer. These connotations will vary in terms of their symbolic significance within segments of the cultural order (Bury, 1991).

Changes in symptoms over time may impact social responses, and these will in turn influence experience. Anne no longer deals with daily symptoms of endometriosis and has been able to resume normal social interactions. She is now free from the pain and insecurities associated with endometriosis and feels confident and in control. On the other hand, Estelle has recently been diagnosed and currently feels overwhelmed by the pain and experience of endometriosis. Her relational patterns have been affected and she has begun to question her identity.

All five participants referred to the importance of their connections to family, friends and other sufferers. These connections provide a network of support that helps them cope with endometriosis. For Phillipa her connections to her family and husband are a source of great support. These connections have helped her create a new identity following her severe medical treatment and have allowed her to gain control over her life by moving forward. Her relationship with her husband has provided Phillipa with much needed reassurance that she is a 'whole' person. Anne and Charlene also highlighted a strong connection to their partners who function as anchors in their lives. The youngest participants, Estelle and Kaitlyn, connected with their mothers, who were able to offer support and guidance in light of a lack of information and an uncertain future.

Connections can have a positive effect on the individual's ability to cope with her disease. In the participants' stories their connections form part of their coping strategies. The participants' acknowledged that their connections were often limited to their immediate family and professionals. Estelle was the only participant who made a connection with another sufferer. This connection has helped validate her symptoms

and has enabled her to speak to someone who can empathise with her situation and experiences.

The other participants all noted that it is extremely difficult to find other sufferers and that support groups in South Africa are not easily accessible. However, they all indicated that they would appreciate the opportunity to meet and talk to other sufferers in order to connect with a community of women with experiences similar to their own.

Most women experiencing endometriosis do not seek pity, yet the support received from friends and family is often tinged with pity. Receiving support from women diagnosed with endometriosis and other gynaecological problems is different as they are able to empathise with the situation rather than merely sympathise (Salzer, 1991). Women often experience relief when talking to others with endometriosis, as they learn that others share their feelings. In the company of other sufferers there is no need to guard against hurtful comments and women are able to share their suffering and gain validation for their symptoms.

However, many women do have misconceptions about joining a support group. These misconceptions may have prevented some of the participants from making use of this valuable support system. Kaitlyn was under the impression that the women in the support groups would all be older and that the issues raised would focus on infertility. This misconception is related to myths about endometriosis, which are often initiated by the medical profession and maintained by the media.

Despite establishing networks of support and connection, the participants also experienced disconnection within their lives. Estelle received support from her mother but still felt that she had to deal with the effects of endometriosis alone. She experienced disconnection and isolation from her partner and friends and she felt unable to share her concerns with them. Kaitlyn detailed similar experiences. She stated that although her friends were sympathetic, they were unable to grasp the full impact that endometriosis had on her life and failed to understand the chronic nature of the disease. This disconnection is often linked to the fear of being judged or labelled. The social stigma associated with gynaecological problems and infertility

often results in sufferers being condemned to silence (Penn, 2001; Weinstein, 1992). This silence results in experiences of disconnection from friends and family.

Phillippa experienced disconnection in her relationship with her younger sister who was unable to handle the emotional turmoil created by endometriosis. She refused to accept Phillippa's self-destructive behaviour and chose to disengage from the relationship. Phillippa also finds it difficult to interact with women who are pregnant or women who have recently given birth. This disconnection is a protective mechanism that helps her cope with her feelings of loss surrounding her own inability to have children. She recognises that interacting with pregnant women or women with babies triggers emotional outbursts and leads to feelings of jealousy.

A theme of disconnection from her family was present in Charlene's story. The process of being stigmatized as childless combined with her family's refusal to acknowledge or address the issue created a rift that led to disconnection.

Estelle employs a strategy of denial in an attempt to reduce disconnections with family and friends. Instead of sharing her feelings of pain and anguish she attempts to please those around her. This allows her to focus on the feelings of others, providing her with a refuge from the reality of her disease. For Estelle this denial is part of a coping process and allows her to emotionally distance herself from the reality of endometriosis.

The narratives of Kaitlyn, Phillippa and Estelle all contain the theme of rejection. Estelle is extremely concerned that if she is unable to control the impact of endometriosis on her life, her partner will leave her. This belief has led to Estelle experiencing lowered self-esteem and feelings of guilt. Both Phillippa and Kaitlyn spoke about the difficulty of being single and suffering from endometriosis and the difficulties they encounter with men. Salzer (1991) found that it is not uncommon for single women diagnosed with endometriosis to withdraw from their relationships or to maintain contacts on a purely superficial level. At the core of this withdrawal is the fear of rejection. This fear is based on a negative self-image. These women often feel defective and believe that they are not desirable to men (Salzer, 1991). Phillippa experienced previous relationships where men left her because of her inability to bear children. This has had a negative impact on her self-worth. Kaitlyn indicated her



concern that her possible infertility might impact future relationships, but also displayed maturity by stating that a man should choose her based on more than just her ability to have children. She does not feel pressured to disclose her endometriosis status to potential suitors and believes that should she enter a long-term or serious relationship she will rely on honest and open communication regarding her disease and possible fertility problems.

### **Emotional Well-Being and Physical Functioning**

Endometriosis influences the emotional well-being and physical health of millions of women worldwide. Endometriosis is often linked to a lack of physical activity (Guidone, 2010). The most significant consequence of endometriosis is infertility.

#### **Fear**

The diagnosis of a chronic disease is frequently associated with fear related to the possibility of life-long physical disability. However, chronic disease is also related to fears concerning other spheres of life.

A diagnosis of endometriosis is often initially accompanied by feelings of relief, disbelief and shock. These feelings quickly give way to a variety of fears and anxieties (Weinstein, 1992). As a result of the uncertainty surrounding endometriosis, women often experience fears concerning the long-term consequences of the disease. They also experience fear regarding the various tests and treatments. These fears may motivate some individuals to seek information and develop coping strategies, but may lead other individuals to feel overwhelmed and retreat into denial (Weinstein, 1992). Salzer (1991) states that infertility patients are second only to terminal cancer patients in their willingness to tolerate any kind of medical treatment.

Estelle experienced a fear of the unknown when she first suspected that she had a serious illness and again when she was faced with surgery. Anne did not experience fear at the time of diagnosis, but did experience a fear of the unknown when her daughter was diagnosed with endometriosis and her fertility was endangered. Estelle

admitted that she finds the unpredictability and recurrence of the disease unsettling and that this has created a sense of trepidation about the future.

The fear of being judged or labelled emerged as a theme from Estelle's story. She hides her pain from others because she is afraid of being seen as weak. Her real experience of pain contrasts strongly with her persona of a positive and independent woman. She also feels concerned that the doctors will label her as inconsiderate if she asks too many questions or appears too needy during her appointments. This fear of being labelled has resulted in Estelle resorting to silence.

Society treats individuals with illness, and especially those with chronic illness, as shameful, morally defected and somehow less than whole (Penn, 2001). Many women fear the judgement of silence and respond by remaining silent about their condition. Endometriosis is surrounded by negative cultural metaphors that make it difficult for women to maintain positive self-perceptions. Penn (2001) suggests that sufferers should make use of new metaphors in order to view the self in a new way.

A fear of physical disability or changes emerged from the stories of Kaitlyn, Estelle, Charlene and Phillippa. Kaitlyn feared the physical side effects of the treatments. According to Strauss et al., (1984) chronic illnesses are multiple illnesses, as the treatments for these illnesses often result in severe symptoms or even other illnesses. Kaitlyn experienced weight gain and problems with her skin that affected her self-confidence. Estelle feared the changes in her sexual relationship and also worried about future complications such as infertility. These issues have led Estelle to question her identity. In addition, her fears are strongly linked to her beliefs about her partner's feelings and her concern over whether he will stay with her in light of these changes. According to Andersen (1984), a unique and powerful cause of distress for women suffering from endometriosis is anticipating and receiving treatments that directly impact their sexuality. These treatments often result in feelings of being different and defective (Weinstein, 1992) and sexual difficulties can compound these feelings. Estelle's diagnosis has caused her to reappraise her body image. She believes that she is less attractive, desirable or feminine than other women and this has resulted in a lack of sexual confidence. Furthermore, it is possible that her partner senses an emotional withdrawal from intimacy and may interpret this as rejection.

Charlene and Phillippa both fear the physical pain that erodes their daily life. The unpredictable nature of endometriosis means that they both live with the fear of the possibility of further physical disability later in life.

### **Sexual Dysfunction**

A diagnosis of endometriosis is often accompanied by the experience of painful intercourse, which frequently leads to feelings of apathy toward sex or a wish to avoid sex completely (Salzer, 1991). Thus, at a time when a woman is likely to crave reassurance and closeness the physical constraints of her body interfere with the pleasure of her sexual relationship. Years of painful intercourse have led to Estelle feeling defective and believing that she is not desirable or feminine. Her continuous pain has eroded her sexual confidence. However, she feels unable to share her pain and apprehension with her partner, leading to misunderstandings and a breakdown in communication. According to Weinstein (1992), many couples experience an erosion of romance and affection following a communication breakdown. In Estelle's case, the loss of intimacy has placed severe strain on her relationship. During the interview Estelle spoke about her concern of being rejected by her partner if she continues to battle with the side effects of endometriosis or if she is unable to have children. These concerns have led to feelings of worthlessness and uncertainty about her future. Lemaire (2004) found that increased uncertainty is associated with increased emotional distress. The relationship between Estelle and her partner demonstrates that although a couple may be living together they can still be isolated from each other (Strzempko Butt & Chesla, 2007). The theme of 'together but alone' focuses on patterns that disrupt mutual understanding, cohesion and connection and instead accentuate pre-existing differences between partners.

### **Pain**

When pain is inadequately controlled it leads to anxiety and stress (Weinstein, 1992). Stress in turn causes insomnia, which increases pain and anxiety. These factors can combine to cause depression, which further exacerbates the experience of pain (Weinstein, 1992). This combination of feelings produces an overwhelming sense of hopelessness, helplessness and despair. The pain process is therefore circular and it is

often difficult to determine the way in which the factors are related. Physicians and patients often search for the physical root of the problem – the source of the pain – without addressing the complexities of the pain experience. Phillipa described her experience of this cycle of pain, which resulted in a sense of a loss of control over her body and its abilities. She became extremely irritable, suffered a loss of self-esteem, experienced extreme uncertainty and became socially isolated. Her feelings of hopelessness manifested in suicidal thoughts and behaviours.

Pain negatively impacts quality of life (Jones, et al., 2004). Kaitlyn, Phillipa and Anne experienced pain during menstruation. Endometriosis sufferers also commonly experience pelvic pain that is unrelated to menstruation. Anne reported lower back pain and Charlene experienced pain in her abdomen. Phillipa suffered from severe pain on a constant basis. At times Phillipa felt unable to get out of bed. All the women reported that when the pain is at its worst they are unable to continue with their normal daily activities. Estelle's experienced pain during or after sexual intercourse. This directly impacted her sexual relationship with her partner and her sexual identity.

Pain can result in individuals feeling trapped by their own bodies. In addition, the anticipation of pain can become all-consuming. When pain persists it becomes habitual and most of the women in this study were unable to remember a time when they did not experience pain. Weinstein (1992) suggests that in order to overcome the pain cycle women need to engage in a pain management program that combines relaxation techniques and counselling in order to correct distorted perceptions and produce constructive responses.

## **Survival**

The participants all displayed a sense of survival and seemed determined to continue to live their lives as normally as possible. A diagnosis of endometriosis constitutes a crisis and adapting to life with endometriosis usually involves five stages: crisis, reaction to diagnosis, mobilization, grief and resolution. According to Weinstein (1992), these stages are all normal and form a necessary part of learning to cope with endometriosis and its long-term impact as a chronic illness.

These stages may be experienced more than once as a result of the experience of multiple crises and losses (Weinstein, 1992). The way in which women adapt to endometriosis is not uniform but is influenced by each woman's environments and relationships. Following her battle with breast cancer, Anne has achieved resolution. She has been able to move from helplessness to equilibrium and looks forward to her future. She has also developed practical strategies to help her daughter cope with the disease and is prepared to deal with any setbacks that may occur. Phillipa is still in the stage of mobilization. She experiences disorder and disequilibrium and often feels out of control or overwhelmed by daily tasks. In this stage a sufferer's life is put on hold and their focus is simply on dealing with the symptoms and improving their health (Weinstein, 1992). Charlene has made a conscious decision to live with the disease, thereby attaining resolution. She is learning to minimize the impact of the disease through the use of alternative treatments. Estelle, the most recently diagnosed participant, is currently in the reaction to diagnosis phase. She is battling to come to terms with the disease and its origins and experiences intense feelings of fear, disbelief and anxiety. At present, Kaitlyn appears to have achieved resolution. She has accepted endometriosis as a part of her life and finds ways to cope with the symptoms that she experiences. She has implemented practical strategies that help her deal with the disease and has redefined her social roles. She has identified goals and is improving her general health.

### **Suffering**

The medical profession understands suffering in terms of pain, loss of function, dying, loss of hope and fear of future pain (Candib, 2002). However, pain is not necessarily the only form of suffering. In fact, pain can occur as the result of suffering.

Suffering transcends pain and is present even in the absence of physical pain. Endometriosis can dominate life even after the pain or symptoms have subsided. For some women the reality of life without children is a constant reminder of their condition while for other women the memory of the experiences associated with endometriosis can be extremely upsetting (Candib, 2002). Suffering mostly occurs at an individual level but it can also occur on a familial level and can transcend

generations (Candib, 2002). Daughters frequently carry the pain of their mothers' experiences of endometriosis.

Candib (2002) suggests that suffering and shame are gendered and that vulnerability is passed down through the generations. Thus, the manner in which a mother deals with her femininity, sexuality and experience of endometriosis is likely to influence her children's approach to women's health issues. Anne displayed no shame when talking about endometriosis and its impact on her life. She encourages open communication with her daughter and her husband. This has created a healthy and participatory environment. Estelle indicated that her father feels embarrassed discussing issues relating to endometriosis. In turn, Estelle is hesitant to talk to her partner about the pain and possible fertility implications of endometriosis. Charlene recognises the impact of her family's silence regarding endometriosis and is determined to change this behaviour and language with her daughter in order to create an environment of open communication and learning.

Healing involves creativity (Candib, 2002). At times healing needs to occur within the individual but at other times healing involves family and community. Kaitlyn found healing through her mother's support and determination to help her improve her quality of life. Phillipa's family and husband rallied around her and created a community that shielded her from further disappointments and provided emotional support and spiritual guidance. This support was fundamental to her physical and emotional recovery. In particular, her husband's reassurance allowed her to re-imagine her future and create a new identity.

### **Conclusion**

The participants' stories demonstrate their vulnerabilities in coping with endometriosis, but they also demonstrate the participants' determination, courage and strength in the face of seeming insurmountable difficulties. These stories celebrate life while acknowledging that life is sometimes messy and taxing.

The process of deconstructing and comparing the stories was important as it allowed for the development of an awareness of the socially constructed world of shared

meaning. Although the experiences contain several similarities each individual's experience remains unique

Endometriosis is neither the beginning nor the end of suffering and it does not define the women in this study. Its lessons of knowledge, education, acceptance and tolerance are applicable to a myriad of settings. Endometriosis enables sufferers to move forward with insight. These sufferers frequently feel a need to enlighten others in order to combat the widespread myths and ignorance that surround this disease.

In the final chapter of this research report the strengths and limitations of this study are evaluated and recommendations for future research are discussed.

## Chapter 6

### CONCLUSION

*“Where shall I begin, please your majesty?” he asked.*

*“Begin at the beginning,” the King said gravely,*

*“And go on till you come to the end: then stop”.*

(Carroll, 1896/2004, p. 197)

In this chapter an attempt is made to evaluate the research in terms of its strengths and weaknesses. Recommendations for future research are also provided. The chapter concludes with a personal reflection concerning the research.

### Evaluating the Study

The study aimed to explore the psychological effects of endometriosis on women in the South African context. The main objective of this study was to provide a more comprehensive understanding of the personal suffering experienced by endometriosis sufferers. It was also hoped having this opportunity to share their stories would help the participants gain new insight and meaning.

The research was grounded within a social constructionist theoretical framework. The study did not aim to quantify or explain the women’s experiences and meanings in terms of measurable data. Rather, the women were engaged as active participants in the research and it was hoped that their descriptions of their experiences of endometriosis would help to provide a greater understanding of the lived experience of endometriosis. The social constructionist stance also allowed the researcher to include her own assumptions, feelings and questions within the research. This inclusion allowed the research to become a co-construction of meaning, making use of available literature, the narratives of the participants and the thoughts of the researcher. This research is thus not simply a reproduction of previous projects, but represents the creation of rich and interesting dialogue.

According to Henning (2005, p. 205), the participants’ ability to make sense of their disease was “embedded in unique contexts and co-created by relationships they hold



with others” (p.205). The participants’ connections with their physicians, other sufferers, friends, family, work colleagues and even the researcher expanded their ability to make sense of endometriosis.

The researcher identified and discussed themes contained in each participant’s story. This was then followed by a comparative analysis of the individual themes in relation to the literature. The researcher believes that the themes identified in this study will contribute to the existing body of literature, thus helping to create a deeper understanding of the complexity of the experience of endometriosis. The existing literature seems to focus on infertility and pain as the main facets of endometriosis and lacks descriptions of the emotional world of endometriosis sufferers. This study has contributed to filling this gap in the literature.

Four broad themes were identified in the women’s stories:

- Relationship with the medical community
- Social functioning
- Emotional well-being and physical functioning
- Transformation

The study found that although physicians attended to the physical needs of their patients the patients’ emotional needs were often disregarded. The nature of endometriosis and the patient’s responses to the diagnosis mean that medical professionals are often called on to fulfil additional roles. The women expressed a need for an expert, a rescuer and someone to guide them. Endometriosis is a chronic disease that can progress over time and the relationship between the patient and the professional may therefore be prolonged. This extended relationship necessitates the development of mutual respect.

The participants found the loss of physical functioning to be particularly difficult to manage. This loss presented itself differently for each participant. It ranged from the loss of sexuality to extreme pain and interference in daily activities. Although the participants described the journey to acceptance and self-awareness as challenging the experience of endometriosis has also precipitated positive change, development and growth in their lives.

Much of the existing literature relating to endometriosis focuses on quantitative studies. This research project acknowledged the contribution of these studies and expanded on the ideas contained in them by delving into the psychological impact of endometriosis. The research was qualitative in nature and facilitated an in-depth exploration of participants' constructed realities. The findings of this study suggest that the length of time before diagnosis, the physician-patient relationship, the experience of pain, the quality of the support network and the ability to assimilate endometriosis into everyday living all impact on individuals responses to endometriosis.

This research also has several limitations. The researcher identified herself as a member of the endometriosis community, having struggled with the disease for over eight years. She therefore had a personal interest in the topic under investigation and this impacted upon the structure of the interviews and the subsequent interpretive process. It is important to recognize that although the data was analysed using appropriate qualitative methods, the results are influenced by the researcher's experiences, opinions, interpretation and understanding of the data.

It could also be argued that the sample was too small to provide meaningful information. However, this small sample size is in keeping with the nature of qualitative research, which does not aim to generalize results but rather strives for applicability and utility.

The researcher used purposive and snowball sampling to find participants for this research and this represents a potential bias in the sample. The participants all have certain commonalities that enabled them to participate in the research. In particular the participants are all well educated and have access to private sector medical treatment. The diversity of the sample was therefore limited and this in turn limits the research results.

One of the strengths of this research is that through engaging in dialogue with participants the researcher was able to explore unfamiliar topics and raise awareness of the participants' unique understandings of the experience of living with

endometriosis. The research did not seek to establish cause and effect but rather focused on examining the lived experience of endometriosis in relation to the family, cultural and social background of the participants.

Despite these limitations the present study contributes to the existing body of research relating to endometriosis. It also highlights the importance of viewing endometriosis sufferers as multidimensional and complex human beings. This research has generated a range of questions that can serve as starting points for new areas of understanding.

### **Recommendations for Future Research**

The stories and experiences communicated by the participants in this study have illustrated the pervasive nature of endometriosis and have demonstrated the ways in which the disease impacts on virtually all aspects of lived experience. However, the stories also demonstrated that learning to accept and live with this disease can provide a context for growth, transformation and healing.

The literature contains a lot of information relating to the medical aspects of information. However, a research gap exists with regards to an understanding of the lived experience of endometriosis and the impact of the psychological symptoms associated with endometriosis. Questions such as “How are individuals affected by endometriosis?” “How do individuals cope with endometriosis?” and “How can we assist endometriosis sufferers in finding meaning in relation to their disease?” must still be answered.

Based on the findings of this research study it is recommended that future research focus on the impact that endometriosis has on lived experiences. Research should also focus on the role of medical professionals in improving quality of life for women suffering with endometriosis. It is important that gynaecologists and physicians are made aware of the nature of the suffering inflicted by endometriosis and the need to acknowledge women’s concerns relating to the side effects of the treatments offered.

It is hoped that the current study will inform future research in the following fields:

- Improving the physician-patient relationship through creating a collaborative partnership in which women play an active role in their treatment. Shared expertise can improve the quality of treatment received by patients. Professionals need to acknowledge that while they have technical and academic knowledge, their patients are able to contribute their stores of experiential knowledge. Through combining physician and patient expertise it is possible to improve quality of life rather than simply treat symptoms. It is hoped that this interaction will improve the future management of endometriosis and stimulate significant changes in the training of physicians and gynaecologists.
- Some of the themes that emerged during this research study were unexpected and previously disregarded. These themes included the generational legacy of endometriosis and the relational difficulties the women experience within society. These themes require further investigation.
- There is a severe lack of awareness about endometriosis within South Africa. Future research is required to determine the extent and impact of this disease within both the public and private health sectors. This knowledge will allow the medical fraternity and the South African government to improve available support systems and implement awareness campaigns aimed at dispelling the myths surrounding endometriosis.

The research projects recommended above will help to improve the physical and emotional treatment of women with endometriosis.

### **Reflections of the Researcher**

This research has been a journey of insight and exploration. I will not easily forget my encounters with Estelle, Kaitlyn, Anne, Phillipa and Charlene. The purpose of this study was to provide a voice to women who have previously been silenced. During our encounters the participants were able to investigate the losses that they have experienced as a result of their disease. They were also able to examine the impact that endometriosis has had on their identities. It was clear to me that the approaches to endometriosis differed based on the participants' life phases. The younger participants, Estelle and Kaitlyn, are still naïve in their approach to the disease. They

are beginning their adult lives and are developing romantic relationships. In some ways they still believe they are indestructible and that issues of fertility can wait until they are ready to address them. Phillipa is in the process of coming to terms with her 'lost' youth and accepting the fact that she cannot have children. These losses have shattered her perception of herself and she is attempting to recreate her identity. Anne and Charlene have already have children, and thus the fears associated with infertility are no longer relevant to their lives. This has allowed them to make positive strides forward, taking responsibility for their disease and treatments and optimistically adapting to the remaining challenges.

This research has provided me with a privileged opportunity to gain insight into the ways in which women choose to make sense of their diagnosis of endometriosis and the ways in which they face the challenges the disease brings.

### **Conclusion**

It is important to remember that the themes highlighted in this research study do not represent universal truths. This thesis represents one possible way of understanding the impact of endometriosis and acknowledges that there is no single truth. The reader must infer his/her own personal meanings and distinctions regarding issues relating to endometriosis. By providing a descriptive account of the disease, this study aimed to provide valuable information to aid in the understanding of endometriosis.

This study explored the psychological effects of endometriosis. The stories of the women interviewed for this study detailed the multi-faceted suffering experienced by individuals diagnosed with endometriosis. However, their stories also highlighted remarkable strength and determination in the face of disease.

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## **Appendix A**

### **Letter of Information**

Hello, my name is Christy Bennie, a student in the Master's program in Research Psychology at the University of South Africa. I have chosen to explore the psychological effects of endometriosis as my research project and hope that you will agree to participate in my study. As a woman who suffers with endometriosis personally, I understand the complexities of this disease and how it can affect one on a variety of levels. I am particularly interested in how you experience Endometriosis and its impact on various aspects of your life.

The purpose of the study is to explore the psychological effects of endometriosis through the use of an open-ended one-on-one interview, where questions relating to Endometriosis and its impact on you will be asked.

The title of my study is "exploring the psychological effects of endometriosis: a qualitative study". While the information shared during these interviews will be used for the basis of my dissertation in psychology, I also hope that it will benefit you by giving you a platform to tell your story and experience of this disease.

I will use thematic content analysis to analyze the gathered data. As a result, the interview will be transcribed, and with your permission, audio taped. The interview will take approximately one hour.

Participation in this study is entirely voluntary, and any decision not to participate will have no negative bearing on you in any way. Should you agree to participate, you may decide to withdraw from the interview at any stage, regardless of whether you had initially agreed to participate. You may also refuse to answer any of the questions posed during the interview. However, I will undertake to be as sensitive and understanding as possible to your concerns whilst conducting the interview.

Every attempt will be made to ensure the confidentiality of the research participants. As such, only my supervisor Professor Ricky Snyders, and myself as the researcher will have access to the informed consent forms as well as to the gathered data. For the

purpose of the dissertation, no pertinent personal details will be used. You will only be referred to by a pseudonym in order to protect your identity.

I look forward to hearing from you,

Regards

Christy Bennie

Contact Details: 082 466 3556 or [christy@elementalinteriors.co.za](mailto:christy@elementalinteriors.co.za)

Further queries may also be directed to my supervisor at Unisa: Professor Ricky Snyders on (012) 429 8222.

**Appendix B1**  
**Letter of Consent**

I.....have been thoroughly informed regarding the nature of the study, including my participation in it. I hereby consent to participate in a one-on-one interview that is to be conducted by Christy Bennie, a Research Psychology Master's Student, under the supervision of Professor Ricky Snyders at the University of South Africa. I understand that by taking part in this study, I incur no risk of harm to myself and that I have the right to withdraw at any given time during the study, without any negative consequences.

Signed..... Date.....



## Appendix B2

### Letter of consent to be audio taped

I.....have been completely informed that participation in this research involves being audio taped. I am also aware that the researcher, Christy Bennie, as a Research Psychology Master's student at the University of South Africa, will ensure that my anonymity is kept, by restricting review of these tapes to herself and her supervisor, Professor Ricky Snyders. Should a transcriber be used, they will be required to sign a letter of confidentiality and will not be privy to your personal details. I understand that these audio taped materials will be destroyed immediately once the dissertation has been accepted, to ensure my confidentiality and to further guarantee that my responses will not be identifiable, by virtue of replacing my name with a pseudonym.

Signed..... Date.....

## Appendix C

### Eligibility Questionnaire

YOUR INITIALS <div style="border: 1px solid black; width: 40px; height: 20px; margin: 5px auto;"></div>	SUBJECT NUMBER <div style="border: 1px solid black; width: 60px; height: 20px; margin: 5px auto;"></div> For official use only	DATE <div style="display: flex; justify-content: space-around; align-items: center;"> <div style="border: 1px solid black; width: 30px; height: 20px; margin: 5px;"></div> <div style="border: 1px solid black; width: 30px; height: 20px; margin: 5px;"></div> <div style="border: 1px solid black; width: 60px; height: 20px; margin: 5px;"></div> </div> <div style="display: flex; justify-content: space-around; margin-top: 5px;"> <span>DD</span> <span>M</span> <span>YYYY</span> </div>
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#### DEMOGRAPHICS

Date of Birth <div style="display: flex; justify-content: space-around; align-items: center;"> <div style="border: 1px solid black; width: 30px; height: 20px; margin: 5px;"></div> <div style="border: 1px solid black; width: 30px; height: 20px; margin: 5px;"></div> <div style="border: 1px solid black; width: 60px; height: 20px; margin: 5px;"></div> </div> <div style="display: flex; justify-content: space-around; margin-top: 5px;"> <span>Day</span> <span>Month</span> <span>Year</span> </div>
Have you been diagnosed with endometriosis by a gynaecologist? <span style="float: right;"><input type="checkbox"/> Yes    <input type="checkbox"/> No</span>
Have you had laparoscopic surgery or similar for diagnosis / treatment? <span style="float: right;"><input type="checkbox"/> Yes    <input type="checkbox"/> No</span>
If yes, how many? When was it diagnosed? <div style="float: right; margin-top: 10px;">         _____          _____ (year)       </div>
Do you know your severity / grade of endometriosis? <div style="float: right; margin-top: 10px;"> <input type="checkbox"/> Grade I  <input type="checkbox"/> Grade II  <input type="checkbox"/> Grade III  <input type="checkbox"/> Grade IV       </div>
Race / Ethnic Origin <div style="margin-left: 20px;"> <input type="checkbox"/> Caucasian  <input type="checkbox"/> Black  <input type="checkbox"/> Indian  <input type="checkbox"/> Other, Specify _____       </div>

ELIGIBILITY CRITERIA	YES	NO
Have you been diagnosed by a gynaecologist (surgically)?		
Has a specialist medical professional previously diagnosed you with depression?		
Are you currently or have ever taken anti-psychotic drugs?		
Are you pregnant?		
Have you had any children before?		
Have you undergone a hysterectomy?		
Have you been diagnosed or undergone treatment for Cancer?		
Have you undergone or are you currently undergoing any form of immunosuppressive therapy?		

## Appendix D

### Sample of transcribed interviews

SP1: Thank you for being here. Tell me your story of endometriosis.

SP2: Okay, um I was diagnosed in 2003 because I had quite severe um abdominal pains. Um, initially they thought it was my appendix but after having an internal ultrasound done they found a cyst the size of tennis ball. I then had to have surgery to remove the cyst um, and it was then that they discovered that I had stage IV endometriosis. Um, after this I was placed on treatment um, hormone replacement therapy, as well as on a drug called Zoladex. Um, it was not fun. Basically the drug would bring on menopause and you would have all the symptoms of menopause and I guess the hormone replacement therapy was there to basically – to sort-of balance out the Zoladex.

I was on that treatment probably for ... I think I had about three Zoladex injections um over about a year – a year and two or three months. Um, I was told I would not be able to have kids normally. I – I would have to be um assisted in trying to conceive and I was told that um they – there was no certainty as to whether I'd be able to actually carry a child to term and I was 23 years old. I had just been divorced so it was not – it was the worst time in my life – possibly the worst time to be told that there's a clock ticking away and I need to have – or I need to try and have kids as soon as possible.

So I basically didn't really seek any psychological help although I wish I did now in retrospect because obviously the stress of being told something like that so early in – in life, you know, being told that you wouldn't be able to have kids, there was – you know, no certainty that you'd be able to have kids – it was – it was something that was earth shattering, even though I never really thought about having kids at the time, you know. But – and the things is, you don't want someone place a restriction on you especially when its something so fundamental to being a woman, you know, you should – it's every woman's right to be able to have it – have children, you know. Um ... so probably for about two years after that I – I went on the treatment, went off the treatment. I didn't really do much to treat the endometriosis, didn't have much information at that time, was just lead on to believe by the doctors who were treating me that it's something that will – you know, it will ease with time.

Um, and then in 2006 I moved up to Jo'burg. Um, I met my fiancé, got engaged two weeks later, moved up to Jo'burg and just assumed that, you know, we'd be engaged for a while, you know., and low and behold three months later I fell pregnant. And to be told you couldn't have kids and then to fall pregnant, bearing in mind that you're still remember you can't possibly carry this child, you're waiting for a miscarriage, it was the most traumatic time in my life. I think it was much worse than being diagnosed (soft chuckling) because here I was pregnant, being handed this gift that I did not expect but not really being able to enjoy being pregnant – not feeling – not feeling that connection to your child because you're so afraid that you're going to lose the child at any point.

And it was quite amazing that I had no complications whatsoever. It went though – it was probably, you know, uneventful to say and I had my daughter on the 1st of Jan 2007. Um, I obviously – I'm seeing the same gynaecologist and was just told "Oh, now that you've had a kid, I'm sure the endometriosis is going to get better" and all of that. Wasn't put on any specific treatment but was told that if I go onto a pill – um, I think it was Yasmin as the time – it will ease the symptoms of endometriosis because I was – when he checked me up I was – there were a lot of cysts that were coming up. And when he put me onto the pill the cysts seem to disappear. It helped with the cysts but it was – it was like it turned me into a monster (soft chuckling) and I'm already quite a moody person (chuckling), so uh it was just – I honestly used to feel psychotic, that's how bad it was and I just stopped it. I just said, "I can't take this anymore". I didn't consult with the gynaecologist; I just stopped it.

So I went back to him the following year because I usually go and like every year to have a pap smear done and the internal ultrasound and all of that. Went back and he said, "No, you – the thing is you've got more cysts. You need to go back on another um pill. If that one's not working for you I'll give you something with a lower dosage" which is what he did, which is what I was taking a couple of months ago. It was called YAZ, except like a month after I started taking it I started bleeding every single day and after about a month of that going on, I just – I don't know, I guess I've lost faith in the gynaecologist by now. So I didn't go back to him. I just stopped the YAZ and I've started doing research on - on alternatives, on - on more holistic methods of – of treating this illness.

I've started reflexology and I'm trying to do the whole homeopathic route, changing my diet, trying to exercise (chuckling). Um but I think – I think it – the – the um – the actual changes in my body have been quite minor compared to the – the mental changes that've – that have occurred since being diagnosed with the – with the disea – with this illness. Um, it's sort-of ... it's sort-of turned my life upside down in that I was – I was quite carefree, quite happy thinking, you know, my life was going in a specific direction. Coming out of a divorce, you know, just having the strength to actually initiate a process like that was big enough for me and being told this was like – it's almost as if the control that you have ov – over what happens in your life is taken away and you feel absolutely powerless because you know medically there's very little that can be done to cure the disease, especially at stage IV, um and all you do is just manage it and watch and wait.

Um, also when I was diagnosed I was told that it was at stage IV and my bowels were fused to my ovaries. So when I was chatting with the – with the gynae at that time I was told a hysterectomy would be a viable solution because apparently women who've had hysterectomies have had quite a bit of relief and stuff like that. And I found out later on that I would not be able to have a hysterectomy because it's too risky a procedure with having my bowels fused to my ovaries. They don't know the full extent to which it's fused. And I was told things like ag, they would cut into the bowel and I would – it would result in septicaemia or um I would have to have a stoma. So I was given quite crazy possibilities and I honestly thought that at that time that a hysterectomy would really help me. Um, this was when I was

diagnosed but I was – I was not allowed to do it because I was too young and my – the – the professor of gynaecology who was treating me at that time told me that, you know, they don't recommend it when you're so young. Just treat it until you think you're ready to have kids and try and have kids, and if it's still not working and you still want to have a hysterectomy then you can.

Um, ja so that was – that – the fact that I found that my bowels were fused to my ovaries also had a huge impact on how – on how – how I was looking at the disease at the time. Um, obviously it's added to the discomfort um every month because the hormones are linked, so um apart from the pain there's other side effects now. Um ... hmm, I – that's about it.

- SP1: Tell me, living with these side effects and the chronic pain, how does that impact your life? Do you find you don't do things, that you're not as spontaneous now as you used to be?
- SP2: Definitely. Apart from the monthly pains that – which are excruciating, I literally have to stay in bed because I can't handle the pain or medicate and be, you know, just minimally productive. Um I – I've been having pains like during the month, you know, abdominal pains and I think its also affected my mental state as well because I've just become so – like I'm not – I – I mean, I haven't really been – I can't say depressed, you know, but although it – sometimes it does feel like that way. I just cannot deal with it. I can't deal with just normal, simple daily activities. If I could help it I would just stay in bed and not get up at all. Um, I think I probably have been quite apprehensive about going and getting myself diagnosed by a psychologist because I don't want to go on antidepressants. I briefly went through it um before I was diagnosed because of my divorce and it was not fun (soft chuckling). Um ...
- SP1: And your social life?
- SP2: Well obviously it's – it's not as active as it used to be because I have a child now but after I was diagnosed, in fact I had more of a social life because I was trying to hide from this. I was trying to run away from it (soft chuckling) and – it hasn't affected – it hasn't affected my personality because – well I've put it – I've put it into perspective. Then I was hiding from it but now I think I've put it into perspective and given it the label that it deserves and I haven't let it consume my life. Um but I think – I think that just – the thing that I battled the most with, apart from the pain, is just – just that feeling that, you know, you just cannot face the day. You just cannot wake up. I used to work but I couldn't handle the stress because um I was just – I probably just got into the – the worst possible thing I could, you know. I was doing accounts and then I – well I was given this fictitious promotion of being ah the office manager but I was given like 10 times more work to do (soft chuckling), and I was just putting in too much effort and getting nothing out of it. It was very stressful and I left last year in ... I think it was September. Mm, September. And I think it – uh – I think my state of mind has improved greatly since then (soft chuckling). Um I – I wasn't really doing much to change my diet before but I am doing it now and I'm actually seeing results, you know. The – the pain is easing a lot more, um I'm not quite sure about the cysts anymore

because I haven't really went back and checked it out. But I'm planning on going onto proper homeopathic drugs which have been proven to, you know, ease the symptoms. So I think – I think my efforts will actually make a big difference in – in how – how I'm going to be dealing with the symptoms of endometriosis.

SP1: Going back, you spoke about going onto the hormone replacement and the Zoladex right at the beginning.

SP2: Mm.

SP1: Did they prepare you for that?

SP2: Mm-mm [indicates in the negative].

SP1: And what kind of effects did that have on how you felt about yourself being on those drugs?

SP2: Well firstly, Zoladex is something that's administered into your abdomen. It's like the size of an epidural needle and it's – do you know what I'm talking about? And they inject it into your stomach. Because I was going to a – a public hospital um it's apparently – well it's – I worked at the hospital so that was why I was being treated – it's - it's Albert Luthuli Hospital in – in Durban. It's quite a – well it's supposed to be quite a, you know, state of the art, first of its kind in the country, you know, hospital. Um, I was later told by a – a nurse who was in um – in a private hospital that they're supposed to have given me a local anaesthetic before they were supposed – injected me. They just did it and I have such a high pain threshold, thanks to the endometriosis, that I never noticed it, you know. And I would get the injection and go to back to work, yet I was supposed to have gotten the injection and I was supposed to have – went home and rested because apparently there were um fatalities because of the – the drug not settling properly into your system. It's an oil-based drug that's slow release, something like that.

Um, the side effects from it were – it was menopause. Being 23 years old, waking up in the middle of the night with hot flushes, feeling like, you know, a cranky old woman all the time. Um ... ja but – there weren't any other major side effects. Mentally obviously it was something I was running away from so I didn't feel it. I didn't even want to feel it and I guess I was doing everything possible to run away from it. I was binge drinking, going out clubbing, doing everything (soft chuckling) I was not supposed to do. I did it because at that time it masked – it masked the actual pain of having to sit down and think about the – the reality of what this illness had brought to my life.

SP1: Did you feel less feminine when you were diagnosed and the possibility of –

SP2: No.

SP1: -- not being able to have children?

- SP2: I didn't feel less feminine. I felt ... well not unproductive, that's not the word I'm looking for. ... Mm, I – I guess I felt like I – I couldn't fulfil all the roles that a woman – well not 'is supposed to' but 'can', you know.
- SP1: It's almost like a guilt that you weren't doing what a woman should be able to do?
- SP2: No, I wasn't – I wasn't – I didn't feel – I didn't feel guilty because I didn't feel like I brought it on myself. I felt (soft chuckling) – I felt quite angry in fact because I'd been through so much already and I just did not need this right now (soft chuckling), you know. Um, I felt – I felt really angry. Anger which I – I'm still carrying with me (soft chuckling) which I still haven't dealt with which is quite destructive um but – no, not really – not guilty. I guess if I had been in a stable relationship I would've felt really guilty because I would've had to fulfil that role and I wouldn't have been able to. Um but when I – when I eventually got engaged like two years later and I realised that now my – my life is following this path, I think that was when I felt – I felt somewhat guilty. I felt somewhat betrayed by my own body, that it couldn't do that.
- SP1: How did you approach your fiancé and telling him about it um and the potential that you might not have children?
- SP2: Well at that point in time I was just upfront about it. I just told him, "This is what I've – this is what's wrong and this is the possibility". I was just – it just – you know, it was just part of a conversation we had. I didn't hype it up to something major because I didn't feel like I was disabled. Even though women can have kids, there is no perquisite that that's the – what you're supposed to do with your life. You can either have kids – get married, have kids; not get married, have kids; or not have kids at all. There is no set way that should live your life. You basically are the author of your own destiny and you do it the way you want to do it. Um, so I felt – my feelings about it were very different from probably what other women – other women would have felt about it.

But it was like – there was also this nagging feeling at the back of my mind, you know, like – well let me just put it into perspective. Before I moved up to Jo'burg I went to see a clairvoyant much against my resistance (soft chuckling) but one of my crazy friends told me, "Let's go do it". Went to see a clairvoyant and obviously the first question I asked was, "Am I going to have kids" and she said, "Yes, you're going to have two kids. Your first kid's going to be a little girl. I can already see her standing next to you". And to think of that, this – this was three days before I met my fiancé. I met him on the first of Jan and I had my daughter on the first of Jan as well. So I'm – when I met him, it was just – you know this feeling that you have like – like you're waiting for this person to come into your life but you just don't know when it's going to happen, whether it's going to happen the way you want it to, what sort of process is going to be involved. So it was just this – this weird longing to have, you know, just – I'm waiting for my daughter but I don't know when she's going to get her. That sort of thing and – well and he was completely understanding about it. He said "There's no pressure" because obviously – well, he's very ambitious and career orientated and he

said, "There's no pressure" you know, "we've got lots of years and if we can't have kids we'll adopt". So I didn't have the sort-of pressure or sort-of expectation hanging over my head.

SP1: So he's been very supportive and understanding –

SP2: He's been completely supportive. Um ... Ja. so when I found out I was pregnant it was – firstly it was traumatic because I – well, three months of knowing someone and then you're pregnant, I – I – well I didn't have any set idea of how I wanted to have kids. You know, I didn't say, "Oh, I'm going to have – get married, white picket fence" that sort of thing, "and have kids". Basically it happened when it was supposed to happen but at that point I was like thrown into the deep end again. And I'm quite against abortion; I've always been against it. So that was not a choice for me even though it was still early in our relationship and I'd just moved up to a new city – a city which I'd visited like once before. I was completely in the deep end again and I said, "You know what, I'm – even though – even the – the – the results of this could be quite painful if I lose my child or if it's quite a difficult pregnancy, I'm going to take the chance simply because ... why not? I've got nothing to lose".

SP1: Your family, how did they react when you were diagnosed? Did they have any --

SP2: Because there's so little information around the subject they obviously didn't know exactly what was wrong with me. And I obviously was not on very good terms with them because of the divorce, because I had chosen to get divorced. My parents are quite dedicated Christians and I'm not. I chose to actually leave the religion just before I was diagnosed. I basically altered the – the way in which I looked at my life, like my perspective changed completely. I think that actually helped me come to terms with endometriosis quite a bit because I didn't send myself off on a pity party for too long or whatever, I just got on with my life. Um ... ja, that - that's – well, there wasn't much that I could explain to my – my parents or my family because – well I have – I have other relatives, not immediate – well not – I've got cousins who have endometriosis but it's not called endometriosis, they just can't have kids. So there's no name given to it in that sort-of circle and everyone just assumed that would be me, you know. I wouldn't have kids and that would be my life. So.

SP1: You've had quite a lot of miscommunication with the medical field in the process and I'm picking up sort-of a loss of faith in the medical profession definitely from you. You don't feel that they prepared you at all really –

SP2: Mm-mm [indicates in the negative].

SP1: -- for the – everything that you were going potentially have to –

SP2: Mm-mm, not at all.

SP1: -- experience.



SP2: Actually – well, when I was diagnosed – after – after I was diagnosed I went onto um – I tried cognitive behavioural therapy which I would say helped to a certain degree but obviously it was done just for a couple of months. And I think with endometriosis it needs to be – it needs to have a constant voice. You need to be able to talk to someone about it all the time, whenever you feel like – um because essentially amongst normal women you don't really fit in. You're not like them. They don't have the same um ... the same concerns that you do. It's like you're walking around with this umbrella over your head (soft chuckling) and everybody else is just running around in the sunshine, you know. Um, so I guess you feel quite isolated and when you get to meet other women who are like you, it's like meeting a sister. It's like meeting someone who just – who knows you and understands your pain because you can't basically explain it to a non-endo person. You can't explain it. They will not understand you. They'll think you're quite nuts actually. So.

SP1: So do you find you generally don't tell people in your sort-of friend circle?

SP2: No, my friends know um because I'm the kind of person who – I'm not ashamed of who I am and endometriosis is part of who I am. So my friends know. I'm – I don't restrict myself to being friends with only people who are – have endometriosis. I have a wide circle of friends but what I'm saying is, you can be alone in a room full of people. That – it's that sort of scenario, you know, um and you will not necessarily connect with someone on – on that level, you know. So.

SP1: Do you worry about your daughter potentially having this disease?

SP2: Excessively. Excessively. Um but I'm – I'm actually quite happy that I have – I have information and I will be able to – to notice things with her that my mom did not notice with me and I will get her the help necessary should that happen. Um, there's no certainty that it will but should it happen, I – I'm – I feel that I'm equipped to give her better advice, to point her in the right direction and basically be able to shepherd her, you know. Nobody did that for me and that is – that was huge, you know, not being able to have someone to direct to – a comment or something, you know. Mm.

SP1: You also mentioned earlier that when you went onto the pill, I think Yasmin, it - you felt sort-of psychotic. Tell me sort-of what made you feel psychotic?

SP2: After taking it for about – geez, I think it – well, do you – do you know how it works when you take the pill? You've got to basically use it to skip your periods. So it's not natural. You should not be doing that (soft chuckling). And I used to feel like – like if someone left a cupboard open or forgot to put the lid on something. I honestly felt like – I could see – I could see myself literally tearing things off the wall, shattering everything around me (giggle). It was quite – it was quite insane being able to visualise the – a psychotic outbreak, you know. Not actually – I never had psychotic outbreaks (soft chuckling) like that. Um, I used to scream and shout a lot and, you know, just go off in a huff. Um but it's actually this feeling that comes over you. You're completely irrational. You feel like you're going to do things that you normally wouldn't do and it's quite scary that something that – that a drug can

make – can turn you into a monster literally in like, you know, a couple of months, so.

SP1: Sort-of feelings of frustration and anger –

SP2: Extreme frustration and anger, like you – you basically want to scream your head off.

SP1: Did you sort-of feel like your body didn't belong to you anymore?

SP2: Ah - um I felt my mind didn't belong to me anymore (chuckling). My body was – was doing okay at that time; it was my mind that was failing me (soft chuckling). It's just an extreme sense of – of insanity that you feel and my gynaecologist did not understand it. He is this extremely calm person who – almost like serial-killer calm, like you know, he looks at you and it's like, "Oh okay, no that's fine" and you're thinking, "It's not fine. It's not fine all" you know. "I – you're making me feel like a lab rat."

SP1: Did you have emotional outbursts as well, --

SP2: Not with –

SP1: -- crying?

SP2: Well ja, I used to cry a lot. That's possibly the only non-invasive thing you can do (chuckling), go off into a corner and cry. Yes (soft chuckling).

SP1: And how did you husband react to all of that?

SP2: Well – I told you I'm – I'm naturally a moody person. I'm quite psychotic myself. So this really give – gave me this extreme sense of, you know, insanity. Um, well he obviously noticed it because it was in his face all the time and – which is why I had to go back to the gynae and find ways of fixing it. And he actually suggested, you know, eliminating stress by leaving work and finding something to do that makes me happy because I think he probably couldn't deal (soft chuckling) – deal with this stress ball in his house.

SP1: Did you feel that it placed sort-of extra pressure on your relationship?

SP2: Of course it did; I wanted to kill him all the time (laughing).

SP1: Shame, poor man (laughing). Um what else would you like to sort-of talk about – or that's come up during your time? I mean, do you worry about your future, having to still live with this for potentially another 20 years before you have a hysterectomy?

SP2: No. I think – I think one of the main things I've done is that I've just let go of it. However the – the future chooses to unfold it unfolds. I can't stress about it because stress is bad, I've realised that (soft chuckling) and I'm just basically living my life one day at a time, just enjoying every little thing that I can, from it being a cup of tea with a friend to a sunset or a sunrise, you know. Just – I'm trying to be very present in my life because I've come to realise that very little is within my control. So I want to basically enjoy every bit of

it and be as grateful for every little thing that I have. Apart from all of the – the – um – the, you know, the medication and the exercise and the diet, my mind is going to be the thing that helps me get through this and I need to focus a lot on balancing it out and improving my clarity so that I can see my way through this, you know, like I'm not just going to be completely overrun, you know. I mean, if I'm diagnosed with some other side effect of this illness I must be able to have the strength to deal with it. So that's what I'm doing now. I'm just trying to prepare myself as much as possible for anything that can happen but also being fully present and enjoying every single day.

SP1: If you think about mother or your grandmother, did either of them potentially have fertility problems? Did they have problems carrying children?

SP2: My mom's mother had 18 children.

SP1: Okay.

SP2: My dad's mother had seven. My mom had three. They weren't any fertility problems (soft chuckling). No signs of endometriosis. They were completely normal. So it was a shot in the dark; it just came out of nowhere. I didn't expect it ... but I'm actually happy that it's me, you know. I can deal with this. I'm – I'm coping. So.

SP1: When you think about endometriosis in South Africa, obviously there's not a lot of information out there. Do you think it's important that we improve what is out there, educate medical professionals?

SP2: Knowledge is power. There's very little of that circulating at the moment. I mean, I just – I – I was lucky that I would – just wasn't given any information. I shudder to think about the – the girls who are given the wrong information (soft chuckling), you know. Um, I think that – I think that medical professional – professionals are not given the proper training when it comes to endometriosis. They just focus on the physical side of it which is not – which is not a complete human being because we're not just made up of physical body, you know. There – there is the intangible side to us that affects the physical side greatly. And I – I don't think that they – that it's something that needs to be addressed. I think they do need proper training to deal with patients with endometriosis. And it's also quite shocking that there are so few specialists out there, so few endometriosis specialists. I mean, you just Google it and nothing comes up; you get all of these American guys. There's so many overseas doctors that have realised that there's a need, you know, to be – to specialise in this field.

And even this – the lady I was telling you about, Dr Christiane Northrup, her approach is not – it's a holistic approach which is I – which I think is the best approach because it's – it's non-invasive, you know, it's not – you're not putting your body through any more trauma than it needs to because endometriosis is – it's trauma enough, you know. I mean, apart from the laparoscopes and the – the HRT and all of that, I mean they don't really tell you – you – to focus on your mind, focus on your – on your spiritual side to be able to bring your mind and body into balance so you're better able to deal with the – the illness. Nobody tells you that and that's so important.

- SP1: So you're feeling better prepared now going forward?
- SP2: I do. ... Mostly thanks to the internet (chuckling).
- SP1: And um, your final thoughts on endometrioses when you think about it, how do you feel about it?
- SP2: Well ... I think that anything can be overcome. In saying that I'm not saying that endometriosis can be cured but I'm saying that you can equip women to – to be strong, to change their perspective and to work with the disease in – in – in bringing your body back to a state – well not a complete state of healing but obviously to a – to a state that's manageable for you where you will be a better person, you'll be – you know, you'll be able to live your life in a better way and not be completely overcome by the disease, not let it take over your life.
- SP1: Would you say you know your body better now –
- SP2: Ja.
- SP1: -- (than you used to??)?
- SP2: Yes, definitely because before that you just take it for granted that it's doing its business, you know, it's going about its business. Now you're focused on every little action that goes on in your body and you – you want to know more about how your body works in order help it get better
- SP1: Any last thoughts? Anything you'd like to add?
- SP2: Well, we did chat about a support group and I feel strongly that endometriosis does need a voice. It needs a louder voice um and it's something that I'm – I feel very passionate about because it affected me at an age where I was so naïve. And – I mean, you talk about girls being diagnosed at 16, I can imagine that - as a 23-year-old I battled with it, as a 16-year-old I can imagine what those girls must be going through. And I'd like to play a big role in actually helping other women because I think that if you have tools you should – you should, you know, use it to help others. That's it.
- SP1: Okay, thank you.
- (audio ends)