

**Exploring Identity and Illness Narratives: Studying Young Women's Experiences of Cystic
Fibrosis**

By:

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BA, University of Victoria, 2004

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Abstract

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Medical advancements and research initiatives in the last two decades have changed the experience of growing up with a chronic illness. Young people living with Cystic Fibrosis (CF), a chronic, life-threatening, life-limiting, genetic disease, have benefitted from these advances and are living fuller, healthier, longer lives than previously thought possible. Literature exploring the experiences of young people living with CF has traditionally relied on information from caregivers and health care practitioners. It does not reflect the diverse experiences of young people today, or explore the subjective meanings constructed from experiences. Using a social constructionist and narrative inspired methodology, this study explores illness narratives and identity constructions among three young women living with CF. Their narratives are broad and diverse. Shared elements include; making meaning of their illness, and constructing a multi-faceted, relational, layered and flexible sense of self. The layered experiences of CF are one of many important factors influencing their unfolding identity. Relational processes and socially constructed norms and expectations of illness, health, and gender also influence participants' unfolding sense of self. This study demonstrates the value of rich conversations exploring identity construction and illness narratives, and the complexities and nuances within individual experiences.

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Dedication

This thesis is dedicated to my young friend H.G. You were my first teacher about living life as an adolescent with CF: I will never forget you and the lessons you taught me.

Chapter 1: Introduction

Advances in medical knowledge and treatment have enabled more children and young people to survive life-threatening medical conditions and live longer, healthier lives with chronic illness. As a result, the number of children and youth growing up with life long, chronic illness has increased dramatically in the last few decades (Maslow et al., 2010; Suris, Michaud & Viner, 2004). With these advances, research exploring the impact of chronic illness on various areas of children and youths' development has burgeoned. Studies comparing children and adolescents with chronic illness to children and youth growing up in the absence of illness have yielded mixed results, but consistently suggest that young people with chronic illness regularly confront additional challenges and risk factors that impact their wellbeing (Barlow & Ellard, 2005). While there is benefit to discussing chronic illness as a broad concept, it is also advantageous to explore particular experiences of specific illness.

This thesis focuses on specific illness experiences, and explores illness narratives and identity construction of three young women living with cystic fibrosis [CF]; one of the most common chronic and fatal genetic diseases that affects Caucasian children and youth in Canada. Currently, one in 3600 Canadian children is diagnosed with CF each year and at present; no cure exists (Cystic Fibrosis Canada, 2013). Despite its prevalence, and its dangerous and life limiting symptoms, CF remains largely misunderstood and under-represented in mainstream discussions of chronic illnesses. In this chapter, I briefly explain key concepts including the etiology and history of cystic fibrosis a definition of adolescence and a description of my theoretical orientation. I also contextualize the purpose of this study and provide an overview of my thesis describing my research inquiry.

Key Concepts

CF defined. Some researchers conceptualize CF as a spectrum disorder where the severity of the disease depends on the degree and variance of the inherited mutated gene and individuals' age; the symptoms worsen dramatically with age. 'Classical CF' carries multi-system implications (sweat glands, sinuses, lungs, pancreas, gastrointestinal tract and reproductive organs) but atypical manifestations of the illness may not affect any organs (Bush, 2001; Hains, Davies, Quintero & Biller, 2009). Whether perceived as a spectrum or closed diagnosis, cystic fibrosis and its treatment is life altering, complex and intrusive.

CF is present at birth and contracted when an individual inherits two defective copies of the gene responsible for CF; one from each parent. According to CF Canada (2013) roughly one in 25 Canadians is a 'CF carrier', which means they carry one mutated version of the gene responsible for CF. Carriers cannot develop cystic fibrosis, and typically they are not aware they are carriers until they have a child diagnosed with the disease. A carrier's child has a risk of developing CF only if both parents are carriers. When two carriers have a child, there is a 25% chance the child will be born with CF, 50% chance the child will not have CF but will be a carrier, and a 25% the child will not have CF but will be a carrier (CF Canada). Thus biological siblings may all have CF, but not necessarily.

The gene affected by CF is on chromosome 7, and is responsible for encoding a large protein; cystic fibrosis transmembrane regulator (CFTR), which forms a major chloride channel across cell membranes of the sweat glands, sinuses, lungs, pancreas, gastrointestinal tract and reproductive organs (Hains et al., 2009). When working properly CFTR pumps chloride ions out of the cell and inhibits sodium re-absorption. When not working properly, sodium and water are forced to move into the cell, re-absorption is no longer inhibited and unusually thick mucus

secretions build up and plug critical components of multiple organs (Hains et al.). This mucus primarily clogs the lungs leading to life threatening lung infections, and obstructs the digestive system causing malnutrition as the production of natural enzymes that help the body break down and absorb food is dramatically hindered (CF Canada, 2013). The varied and complex symptoms individuals with CF experience when these systems are clogged and obstructed will be discussed in greater detail in chapter 2.

History of CF. Cystic fibrosis was not viewed as a disease in its own right until the 1930's. However Eastern European folklore recognized the severity of symptoms in the eighteenth century warning that; “infants who taste salty to their mother’s kiss will not survive infancy” (Hains et al., 2009, p. 219). The first medical reference to the cluster of symptoms currently indicative of CF is found in early 1900’s medical texts, highlighting problems of malnourishment, pancreatic anomalies, and pneumonia in infants who frequently died in the first year of life (Hains et al.). In the 1960's most children diagnosed with CF did not survive long enough to attend kindergarten. Grim prognoses of significantly impaired quality of life and shortened life expectancy accompanied a child’s diagnosis of CF for most of the twentieth century.

The exponential genetic research initiatives of the 1980's uncovered the affected 'CF gene', and dramatically expanded the medical communities' understanding of the disease (Bush, 2001). Treatment regimes shifted, new therapies were discovered, quality of life for individuals living with CF improved and life expectancy predictions expanded, facilitating a very different experience for individuals living with CF today compared to those living with CF a decade ago (Badlan, 2006; Cystic Fibrosis Canada, 2013). Despite this new genetic understanding of Cystic Fibrosis and advanced treatment possibilities, there is still no cure.

Adjustments to current treatment options, pharmacological and surgical interventions however, have enabled children to survive through adolescence, and well into adulthood (Jessup & Parkinson, 2010) continually surpassing their forecasted life expectancy. CF Canada (2013) cites that presently more than half of Canadians with CF are expected to live into their forties, and nearly 60% of all Canadians currently living with CF are adults. Thanks to advances in medical knowledge and treatment protocols, young adults living with CF today enjoy greater health and flexibility in treatment schedules than those with CF living ten or twenty years ago. Given these changes, existing research may no longer accurately reflect their daily realities, highlighting the importance of exploring young peoples' current experiences of living with CF (Pfeffer, Pfeffer & Hodson, 2003; Quon & Aitken, 2012).

Adolescence. In this study 'adolescence' refers to individuals between the ages of 16-22, referenced in the literature as 'middle' and 'late' adolescence (Kroger, 2007), and the terms young people, youth, and adolescents will be used interchangeably. Within Euro western culture, this time period is constructed and revered as a one of optimum health and vitality. Intersecting biological, psychological and sociological developments influence young peoples' experiences of themselves and their larger world. Increasingly complex cognitive reasoning abilities combined with diverse socially and culturally constructed roles and responsibilities provide adolescents with opportunities to actively construct and perform a variety of identity options previously unavailable. Adolescents are required to consciously make decisions that require them to reflect about who they are and where they want to go. It is an age and stage full of vast developmental change and growth. Living with a chronic illness, particularly an illness like CF where the symptoms worsen during adolescence, undoubtedly complicates this convoluted time of life. This period of adolescence was chosen precisely because of the complex interplay

between adolescents' unique abilities, possibilities and responsibilities, while balancing a tumultuous challenges of an unpredictable chronic illness.

Social construction theoretical orientation. My theoretical orientation and methodology are discussed in greater detail in chapter 3 but it is important to note my understanding of knowledge and the self are both informed by a social constructionist perspective. Namely that knowledge is not 'out there' to be discovered but continually co-constructed through relational processes. Likewise, rather than perceiving the self as an internal, fixed and stable construct, it is created through relational processes, continually in flux (Gergen, 2009). For the purposes of this research I worked within a constructionist framework to explore the construction of illnesses narratives and identity of young women with CF.

Narrative inspired qualitative inquiry. It is widely acknowledged that individuals define themselves and their experiences through narratives and are in turn shaped by the meta-narratives of the broader cultural and temporal climate. These stories are continually created, heard and silenced in the context of illness as individuals strive to make sense of body and symptom experiences; questions of identity and self are intricately linked to these constructed narratives. The self then, is continually reconstructed through the telling and hearing of these narratives (Frank, 2010; Holloway & Freshwater, 2007). Frank (1995; 2010) has influenced how I view these accounts, and the meanings constructed by participants about their experiences. His earlier work exploring narrative frameworks as a tool to make meaning of illness, and later writings highlighting the capacity of stories and dialogical narrative analysis are woven through my interpretations.

To elicit richly descriptive information about events and constructed meanings, I embraced a narrative inspired, generic qualitative methodology. This methodology fits naturally within this

study and social constructionist paradigm, given its profound ability to explore complex subjective experiences of suffering, pain, transitions and disruptions; experiences that are ever present in a life with CF (Elliot, 2005). Congruent with this methodology I have relied on interviews as my main data collection method, complemented by participant photographs to add another layer of metaphor and symbolism, reaching beyond the limitations of language.

Purpose of This Study

The potential impact of chronic illnesses on children and youths' constructed identity is widely acknowledged throughout the literature but the lens through which this has been studied appears rather narrow. It is my hope that insight gained from this study will diversify the discussion about identity construction among young women with CF and contribute to literature voicing present day illness experiences.

Historically, the primary sources of information about children and youth's experience of CF and other chronic illnesses have been parental perceptions, health care practitioner impressions, and youth responses to quantitative surveys rather than eliciting the voices of young people themselves (Christian & D'Auria, 1997; Jessup & Parkinson, 2010; Sartain, Clarke & Heyman, 2000). Narratives of chronic illness experiences continue to grow within the literature, but the unstructured perspectives of young people in particular are mute. In this thesis I sought the perspectives of young women living with CF directly, they were treated as experts of their stories and interviewed as the primary sources of 'data'.

The experiences of young adults with cystic fibrosis today differs dramatically from young people living with the illness two decades ago; they are living longer and enjoying greater health and freedom than previously thought possible. Given this, young people have indicated they feel under or inaccurately represented in mainstream and scholarly literature (Jessup &

Parkinson, 2010). Researchers highlight the importance of eliciting the voices of young people currently living with CF to accurately depict their experiences, but a gap remains. I hope this research will contribute to this gap.

Meta analyses of the impact of chronic illnesses often yield inconsistent results given the variation of sample size, definition of chronic illness, disease demographic, specific dimension of the illness experience investigated, element of adolescent 'wellbeing' studied and diversity among comparison control groups (Barlow & Ellard, 2005; Maslow et al., 2010; Piquart, 2012; Suris et al., 2004). Frequently studies exploring experiences of CF utilize quantitative tools to measure levels of compliance, self esteem, and health related quality of life (HRQOL) rather than learning from and eliciting accounts of lived experiences. Few studies review adolescents' narratives primarily for the purpose of learning from their accounts. This is an unfortunate gap, as according to Cardillo (2010) "close attention to the narrative perspectives of those who have grown up with chronic conditions leads to a deeper understanding and appreciation of the experience of difference for these persons" (p. 544) and a richer understanding of the complex interplay of factors shaping their reality.

Finally, the lens that traditionally informs research exploring identity construction among young people with chronic illnesses frequently relies on classical psychological conceptualizations of 'identities' and 'self', perceiving them as something residing within a person to be formed, consolidated and fixed during adolescence. The social constructionist framework guiding this thesis starts from the premise that the self is a social construction, embedded in specific social-relational processes (Gergen, 2011). It suggests a more fluid, relational and flexible self. Rather than seeing the self as an internal, stable entity, and identity as something to be 'achieved', it is perceived as relationally constructed, "continually shifting and changing

according to role demands and interactional processes" (Hansen, 2009, p. 189). Through ongoing interaction the self is continually re-fashioned and identity possibilities unfold, though still limited and shaped by a larger, contextual socio cultural framework. This study contributes to the growing body of literature depicting a more fluid expression of the self.

Overview of Thesis

This study explores the identity construction and illness narratives of three young women with CF, within a contemporary sociopolitical and cultural context. My study is guided by the following questions:

1. How is Cystic Fibrosis storied as part of young women's emerging identity?
2. How do young women living with cystic fibrosis narrate their relationship to their bodies?
3. What are the cultural narratives surrounding illness and wellness that appear to be shaping young women's understanding of their identity and relationship to their body?

This thesis is organized into 6 chapters. The first chapter provided a brief explanation of cystic fibrosis and an overview of the purpose of my study. Relevant research and literature will be reviewed in Chapter Two, organized around the following: cystic fibrosis and chronic illness among adolescents, and identity construction. Chapter three outlines the methodology utilized in this study. Chapter four introduces the reader to the participants. The discussions and findings are explored in Chapter Five. Chapter Six concludes this thesis with a final summary and outlines potential implications for future practitioners, educators, and researchers.

Chapter 2: Literature Review

This chapter provides a review of the literature as it relates to cystic fibrosis and identity. Literature reviewed in this chapter was searched primarily through EBSCO Host, Academic Search Complete, CINAHL, Psych Info, and Google Scholar databases. Key words searched included: adolescence, identity construction, illness narratives, cystic fibrosis and adolescents, chronic illness and adolescence. Only peer reviewed articles were included. The chapter is divided into two sections, the first half discusses the subjective experience of diagnosis, symptoms and treatment of CF, and examines relevant literature and research exploring the experiences of adolescents living with CF and chronic illness in general. The later section reviews prominent philosophies of identity formation, specifically during adolescence. The discussion of identity is extended beyond its psychological roots and literature expanding the conversation to consider alternative narrative and constructionist perspectives is discussed.

Experience of CF

Diagnosis. While parents frequently do not know if either or both are carriers of the CF gene, minimally invasive diagnostic tools have enhanced medical professionals' ability to diagnose the disease in infants and young children with increasing accuracy and efficiency. Many provinces even include CF screening as part of their standard newborn screening tests, increasing the possibility for early diagnosis (CF Canada, 2013). Currently approximately 60% of children with CF are diagnosed in the first year of life and 90% of individuals with CF are diagnosed by the age of 10 (CF Canada). Given the multi systemic nature of the illness, no single clinical feature leads to diagnosis. An infant or young child experiencing symptoms of 'Failure to Thrive' (difficulty absorbing nutrients and digesting foods) would likely undergo a painless 'sweat test' to measure salt levels in the sweat to rule out or indicate the presence of the illness

(Bush, 2001; CF Canada, 2013). For those with an awareness of the illness, upon request genetic testing can be completed to determine if parents are carriers and to diagnose CF prenatally.

Chronic illness research highlights the impact of diagnosis disruptions in changing individuals' perception of self or projected life plans. CF however does not carry this burden for the individual receiving the diagnosis; while the symptoms change and vary in their disruption the underlying disease has always been there. Williams, Corlett, Dowell, Coyle, and Mukhopadhyay (2009) note this may be reversed for people with CF, that the process of identity formation may disrupt the sense of normalcy a family has created around the illness. The onset of illness symptoms disrupts the already disrupted.

Symptoms. After discussing the pathology and diagnosis, it is important to discuss the lived experience of the illness symptoms. The lungs are consistently the most commonly and profoundly bodily system affected by CF; chronic lung infections account for most of the morbidity and virtually all of the mortality among people with CF (Bush, 2001; Hains et al., 2009). CF Canada (2013) states the most common symptoms of CF include; difficulty breathing and life-altering respiratory tract problems including a chronic rattling, wet, mucus filled cough; severe chronic lung infections possibly leading to permanent lung disease or damage. Malabsorption of food and extreme difficulty digesting food are the second most commonly experienced symptom of CF, leading to a plethora of difficulties including poor and slower growth rate, low BMI, decreased energy, gastrointestinal upset, etc. (Bush, 2001). The degree to which these symptoms impact an individuals' ability to carry out activities of daily life and their quality of life varies; some individuals experience greater digestion difficulties and others experience poorer lung function. Regardless which organ system is most profoundly impacted, individuals with CF live under a constant threat of unpredictable illness complications in the

form of new infections, progressive lung deterioration and inevitable recurrent hospital admissions.

The intensity of symptoms changes with age; as individuals grow older, the symptoms worsen and the treatment regimen becomes more demanding and time consuming (Hains et al., 2009; Tyrell, 2001). The experience of illness shifts dramatically during adolescence; felt both physiologically and psychosocially. Physiologically, the body's ability to fight infections may be compromised by the increased demands of pubertal growth, leading to more frequent hospitalizations to treat lung infections and complications. As the lung function is increasingly hindered, individuals find themselves coughing more frequently and intensely to clear the mucus and regain the ability to breathe freely. Additionally, the appearance of a 'barrel chest' may become more prominent in the adolescent/young adult years (Maslow et al., 2012).

The effects of earlier malnutrition may also begin to take a toll and require additional nutritional treatment protocols or surgical implantation of devices for external feeds to increase individuals' caloric intake and combat digestion difficulties (Tyrell, 2001). Adolescents with CF experience 'late onset' puberty as well, leaving them shorter and less developed than their 'typical' peers; a major visible difference distinguishing individuals with CF (Bush, 2001). Approximately 98% of boys with CF are infertile. Fertility rates among women with CF may also be impacted by the illness, but the increased physical stress and strain of pregnancy carries additional risk (Hains et al., 2009). Women are advised to notify their health care team when considering conception, and encouraged to practice specific precautions in addition to safe sex, such as ceasing to take certain medications and following their treatment regime more diligently.

The psychosocial implications of the physiological effects of CF symptoms are complex. The dramatic shift in management of illness and illness progression during the frequently

tumultuous developmental period of adolescence has captured the attention of researchers from multiple disciplines including; nursing, social work, psychology, sociology, and social psychology. These studies primarily focus on treatment adherence (Badlan, 2006; D'Angelo & Lask, 2001; Hains et al., 2009), emotional adjustment (Tyrell, 2001; Jessup & Parkinson, 2010; Williams et al., 2009) and body image (Abbott et al., 2000; Carew, 2001; Sawyer, 1995) and will be discussed in greater detail later in this chapter. Literature exploring young people's experiences is limited since it is only in the last two decades that individuals with CF can anticipate living into their 40's. Medical advances have dramatically shifted the treatment regimen as well, allowing individuals to live lives less disrupted by frequent and labour intensive medical interventions, resulting in a much different lived experience than previously reflected in the literature.

Treatment. Individualized treatment regimes to manage these diverse symptoms are multifaceted, and continually created and adapted by a multidisciplinary health care team. Though illness progression and symptoms differ between individuals, the literature indicates common regimens to relieve discomfort and delay the effects of the disease. These treatments can be painful and extremely time consuming depending on the illness progression. A delicate balancing act is required to manage the recommendations of treatment proven to prolong life and the degree to which individuals can realistically practice and embrace these regimens while still living a 'normal life'. 'Enforcing' treatment regimes is also a frequent battle between children, youth and caregivers, as they strive to strike a balance between 'normal lives' and treatments which facilitate one's ability to function 'normally'. The research of Williams, et al., (2009) suggests that the treatment regimes themselves can be more dominating and disrupting than the symptoms of CF.

Virtually all treatment regimes include a regular program of preventative chest physiotherapy when individuals are feeling well but also when symptoms are exacerbated. This requires individuals with CF to assume a variety of positions and endure a series of chest and back ‘poundings’ to clear the lungs of mucus to minimized fluid build up and enable individuals to breath more easily (Bush, 2001). A variety of new equipment has enabled this physiotherapy to be self administered or conducted by a physiotherapist (when in hospital), a parent (particularly with children), or significant friend or partner. Typically this treatment is conducted twice a day, lasting from 30 minutes to one hour at a time, though frequency and duration is increased when symptoms are exacerbated. Exercise is recommended as a valuable addition to treatment but not as a substitute.

Individuals with CF frequently take medications (bronchodilators) prior to physiotherapy to help loosen the mucus for excretion and clear the airway - these are either inhaled or nebulized, a process lasting at least 30 minutes. Most individuals take a regular dose of antibiotics; tablet, inhaled or through an IV about twice daily following physiotherapy, others may regularly inhale corticosteroids (Bush, 2001). To help with digestion, individuals are required to take a ‘handful’ of enzyme tablets with all foods to enable food to be digested properly and prevent digestion discomfort and the loss of crucial nutrients. It is also important that individuals eat a regular diet of healthy, calorie dense foods. The increased coughing, hard work of breathing, fighting off lung infections and malabsorption caused by CF makes the body burn more energy, requiring individuals with CF to consume 10-30% more calories than their peers. Not only is treatment intrusive, labour intensive and time consuming; it interferes with many ‘normal’ activities of daily life.

CF and Gender

Since the severity of CF symptoms differ between individuals, there is great variation in the survival age and quality of life among individuals with CF. Biological and physiological factors clearly influence the progression and severity of the illness. Recent studies indicate that socioeconomic factors also play a significant role, and identify significant gender differences in levels of morbidity and mortality. Females across the age spectrum have been found to have a shorter life expectancy, more serious respiratory infections and *Pseudomonas aeruginosa* infections at a younger age than male counterparts (Arrington-Sanders et al., 2006; Kulich, Rosenfeld, Goss & Wilmott, 2003). Recent Canadian data (Willis, Miller & Wyn, 2001) suggested the gap is shrinking but the mean survival rate of men has been reported to be 3-8 years longer than that of women. Research has shown that innate biological and physiological attributes explain some of this differential, but suggest that additional factors may also be linked to these gender differences of mortality and morbidity (Gee, Abbott, Conway, Etherington & Webb, 2003; Willis et al., 2001).

While this gender differential is acknowledged few studies have explicitly explored the impact on quality of life and illness progression, while attending to severity of the illness. Willis et al.'s (2001) qualitative study of young people with CF's transition to adulthood, employed a social constructionist perspective and explicitly explored how social constructs of masculinity and femininity may impact illness experiences and influence why females with CF experience a slightly shortened life expectancy. They discovered significant differences in male and female attitudes regarding meaning of life, death, career and body image, which influenced adherence to the medical regimen, and suggest the normative social construction of masculinity and femininity may influence this differential.

Similar to other qualitative studies with young people with CF, (Arrington-Sanders et al., 2006; Gee et al., 2002) the young people interviewed by Willis et al. (2001) saw themselves primarily as young men or young women, who happened to have CF; their ‘illness identity’ was secondary. Willis et al. (2001) propose that this desire to achieve ‘normalcy’, a theme consistently highlighted throughout the literature exploring adolescent’s experience of CF and chronic illness (Christian & Auria, 1997; Gjengedal, Rustøen, Wahl & Hanestad, 2003; Jessup and Parkinson’s, 2010), may lead young people to embrace traditionally defined normative expressions of masculinity and femininity. For example, desirable femininity involves less physical activity (as evidenced by the decline in female’s participation in sports during adolescence) and desired masculine attributes include being more active; both physically and in approaches to health management. Additionally, physical therapy regimes involve coughing and spitting large amounts of mucus which many young women report as ‘gross’ and challenges the dominant notion of femininity and attractiveness, complicating treatment adherence and influencing illness symptom severity.

Traditional notions of masculinity and femininity also colour satisfaction with body shape and size. The young women in Abbott et al.’s (2000) study for example reported fewer problems with body image, weight and eating than their peers without illness, despite their frequently low BMI’s. This may reflect the current cultural preference of thinness rather than psychosocial coping however as the smaller stature of individuals with CF may be desirable for women. This may also influence adherence to recommended high calorie dietary intake, increasing risk complications related to malnutrition. Young men with CF reported lower scores of body satisfaction though maintained a higher BMI, perhaps reflecting the cultural mores that prefers larger, more muscular men (Abbott et al., 2000; Gee et al., 2002). It is interesting to note

that health related quality of life (HRQL) studies among other illness populations have also indicated gender differences, many reporting poorer HRQL among females (Arrington-Sanders, 2006). Clearly the gender differential requires a more complex explanation than purely biological or sociological explanations, and the distinct exploration of the experiences of genders; male, female and transgendered, is warranted.

Chronic Illness, CF and Adolescence

The number of children and youth growing up with life long, chronic illnesses has increased dramatically in the last two decades (Maslow, et al., 2010; Suris, et al., 2004). Recent studies found that as many as 15% of children and youth across the globe have a chronic health condition (van der Lee, Mokkink, Grootenhuis, Heymans & Offringa, 2007, as cited by Pinquart, 2012). While studies comparing children and adolescents with chronic illnesses to children and youth growing up with the absence of illness highlight many similarities, the research also shows that young people with chronic illnesses consistently face additional unique challenges due to their illnesses (Barlow & Ellard, 2005; Maslow et al., 2010). In spite of these difficulties, studies suggest that adolescents and families cope ‘well’ with the stress of CF (Tyrell, 2001).

Research exploring the impact of chronic illnesses has burgeoned in the last few decades. The study of the experiences of individuals living with chronic illnesses has been examined through qualitative and quantitative lenses and in a cluster (similar diseases grouped together) or categorical (disease specific) fashion; highlighting the commonalities that cross disease categories and those experiences that are disease specific. While many similarities exist among children and youth with chronic illnesses, CF carries unique challenges, experiences and prognoses. Researchers have begun pointing to the necessity of more illness specific studies, representing the perspectives of young people in particular to facilitate a richer and more diverse

discussion within the literature (Badlan, 2006). Since children live longer with CF, researchers stress it is particularly important and timely to explicitly and holistically explore the experiences of adolescents and young adults not previously recognized in the literature (Tyrell, 2001). Young people in Lester's (2001) study indicated difficulty developing emotional maturity or ability to take on adult responsibilities because no one made plans or equipped them with these skills; they were not expected to live this long. Currently the perspectives within the literature primarily belong to health care practitioners or caregivers so sentiments such as those were not present, the voices of young people themselves remain noticeably and regrettably absent (Williams, et al., 2009).

Regardless of the manner in which chronic illness is studied, Cardillo's (2010) review of the literature found that young people growing up with chronic illnesses experience numerous challenges that continue into adulthood and experience themselves as *different* from their peers. Unfortunately this is frequently exacerbated during adolescence, a period of time when *not* being perceived as different from one's peers is particularly desirable.

Quantitative quality of life and psychosocial well-being studies comparing young people with CF to 'healthy' peers without CF have yielded mixed results. Some indicated no difference and others indicated a higher prevalence of adjustment difficulties presenting as internalized disorders and increased stress, particularly as the illness worsened (Hains et al., 2009; Pfeffer et al., 2003). Thompson (1998, as cited by Jessup & Parkinson) explored the experiences of young people living with CF and highlighted that onerous tasks of daily treatment demands may elicit oppositional behaviour impacting compliance and health management. This has led to a plethora of studies in the last 20 years studying compliance levels. However, this is frequently examined through a quantitative lens reporting compliance scores versus qualitative explorations to

facilitate an increased understanding of complex factors supporting or inhibiting compliance (Badlan, 2006).

Researchers and practitioners stress the importance of including psychosocial evaluations in the management of the care of an adolescent rather than solely focusing on specific disease management as the impact of illness is felt holistically; spanning physical, cognitive, and psychosocial domains (Burns, 2006; Cardillo, 2010; Suris, et al., 2004). While the spiritual domain is not readily reflected in the literature, it can be inferred that this aspect is also profoundly impacted. In summarizing the findings across these mainstream domains my intention is not to perpetuate a compartmentalized view of the human experience of illness, but rather report the findings as they are currently discussed in the scholarly literature. As reflected in fundamental holistic Child and Youth care values and philosophies, the domains are profoundly interrelated, humans cannot be neatly compartmentalized into different areas of function.

Physical. The presence of chronic illness frequently affects normative physical growth resulting in various impairments to functioning and/or disability. Categorical studies looking at CF in particular note that this illness can carry a dramatic physical impact. As previously noted, Cystic Fibrosis impacts the timing of puberty causing many adolescents to be shorter in stature and reach puberty at a later age than their peers. Additionally these delays may impact the disease itself as the onset of pubertal hormones may affect the disease parameters (Bush, 2001; Suris et al., 2004). CF also impacts individuals' ability to digest foods, leading to nutrition difficulties forcing many young people with CF to be smaller in height and weight, or experience various degrees of debilitating gastrointestinal upset (Abbott et al., 2000). As noted above, Cystic Fibrosis wreaks havoc on a young person's lung function, thus young people with CF are

particularly prone to contracting dangerous lung infections such as pneumonia. Additionally, their performance (and enjoyment) of athletic activities is impacted by the difference in lung capacity, since they have difficulty catching their breath and physical exertion is interrupted by intense bouts of coughing to clear the chest of mucus and breathe normally.

Cognitive. While some metabolic disorders profoundly impact neurological maturation and functioning, Cystic Fibrosis does not. However, reoccurring illnesses and treatment regimes may result in adolescents missing more school than their peers thus indirectly impacting their education achievements and perception of cognitive abilities or opportunities. Suris et al. (2004) found in their review of the literature that adolescents with chronic illnesses are more likely to ‘skip’ school, missing more class than can be attributed to health problems, citing school absenteeism as a frequent problem among youth with chronic illnesses. These school absences can profoundly impact an adolescent’s feeling of belonging to their educational community and influence peer connections and future academic/vocational aspirations.

Directly related to future vocational and academic aspirations is the shifting goal posts of life expectancy. Adolescents with CF today can consider their futures in a manner those living with CF in previous generations could not. Hains et al. (2009) cite a large variance among studies measuring psychological impairments (primarily internalizing anxiety disorders) among young people with CF, but indicate that young people report “feelings of stress related to coping with adherence and declining health especially while trying to navigate the developmental transition and markers of teenage years” (p. 227). It is important to recognize that these additional stresses do not create a causal link to adjustment difficulties; many individuals report positive consequences of living with a chronic illness, thus exploration of the meanings attached to these additional stressors is crucial.

Psychosocial. Researchers have demonstrated that CF takes a toll on an entire family system. It has been correlated with maternal depression, paternal withdrawal and divorce rates double those in the general population and among parents of children with other chronic conditions (Carew, 2001 as cited by Jessup & Parkinson, 2010), undoubtedly adding stress and strain felt by the adolescent.

Qualitative studies explicitly exploring experiences of young people with CF highlight a theme of striving to maintain a sense of ‘normalcy’ (Christian & Auria, 1997; Gjengedal, et al., 2003). Jessup and Parkinson’s (2010) qualitative study of eight young people living with CF (aged 2-21) and their families is one of the few qualitative studies of lived experiences of individuals with CF. Eight common themes permeated the experiences of the participants, shifting from foreground to background, suggesting that these children and families pursue a future that is “both threatened and continually redefined” (p. 355). Highlighted in this study was difficulty redefining notions of a normal ‘future’ as the goal posts for survival continue to shift. Young people with CF in Badlan’s (2006) qualitative study exploring experiences of youth living with CF and impacts on compliance to treatment regimes, indicated a tension between their strong desire to be seen as ‘normal’ and feeling like an ‘impostor’ in the normal world, particularly as they aged. The treatment necessary to lead ‘normal’ lives accentuated their perceived difference. As CF is no longer just a childhood disease, Jessup and Parkinson (2010) found young adults in several studies reported they felt a lack of self-representation in the mainstream medical literature available to them, perpetuating their sense of perceived difference.

The literature also suggests that chronic illnesses such as CF affect identity, self-image and ego development (Suris et al., 2004). While existing studies highlight themes and tensions few explicitly explore perceptions of identity and self with these youth. Those that explore

elements of identity formation rely largely on quantitative tools, or semi structured interviews to measure identity statuses. Luyckx et al.'s (2008) research for example is an exemplar of typical studies in this area. These researchers utilized identity statuses presented by Erikson and Marcia to study identity development among young adults who have diabetes. The results categorized participants in various closed states of internal identity formation, moving through predictable stages to arrive at various identity 'achievements' or 'commitments', and compared results to peers who do not have diabetes. Rather than qualitatively explore the experiences of identity formation, these researchers (and many other identity studies) utilized identity status findings to draw hypotheses and chart the relationship between identity development and compliance and/or coping.

An exception to this trend is Badlan's (2006) qualitative study exploring the subjective experience of life with CF. Participants in this study explicitly discussed the 'self' and the perception of 'being normal' and reported difficulty discerning what caused them to be considered 'unhealthy'. They questioned how the self requiring medical treatment differs from the self engaging in every day activities, particularly when those medical treatments enable participation in 'normal' every day activities. Many elements of the youths' lives follow a 'normal' trajectory but this is disrupted by daily medication, physiotherapy, illness symptoms and occasional hospitalization. Their lives are ruled by a different kind of 'normal', which impacts their sense of who they are. Additionally, participants in Jessup and Parkinson's (2010) qualitative study indicated the tenuous relationship they had with their potentially unreliable bodies, which are "both the site of disease and necessary for existence... labeled, quantified, assessed, placed under surveillance, and stamped with a 'use-by' date that will surely, relentlessly, run out" (p. 358). The relationship between the self and other, and personal identity

is complicated for most adolescents, but these studies have demonstrated the additional complexities experienced by youth with chronic illness and CF in particular.

Connection with peers is an important source of support for adolescents as they engage in identity construction (Maslow et al., 2010; Suris, et al., 2004); CF is one of the few chronic illnesses where members of the medical community discourage face-to-face peer support. Cross infection and the spread of emerging, dangerous bacteria between individuals with CF led to medical professionals to create this protocol (Badlan, 2006; Bush, 2001). While important to their physical health, this segregation has the potential to further individualize and isolate their experiences, complicating their identity construction and typical adolescent struggles.

Adolescence is recognized as a time of vast developmental change and growth as youth engage in the process of constructing their identities. Living with a chronic illness undoubtedly complicates this process. This is particularly likely among youth with CF; as the symptoms worsen with age, so do the demands and constraints involved in treating these symptoms. In Badlan's (2006) study of young adults with CF, participants noted they assumed more independence and autonomy with their illness management by the age of 16. While this shift in responsibility occurred gradually, they reported the increased demands were onerous and interfered with perceptions of a 'normal' life. Additionally, as youth think about their future; careers and partners, these plans are hindered by illness factors such as shortened life expectancy, impending medical complications, potentially different physical appearances and possible reproductive complications (Hains et al., 2009).

Identity

Questions regarding identity development and formation have captured the attention of Euro-Western social scientists, psychologists and researchers for decades. Traditionally viewed through a psychological lens, contemporary perspectives on identity span a plethora of disciplines and frameworks, demonstrating the complex and intricate nature of the concept. The literature and discourse within each of these world-views is vast and diverse; a thorough review of these theories is beyond the scope of this work. The following discussion offers a brief review of influential identity theories and explores and justifies the frameworks embraced in this thesis. It is important to note that an in-depth theoretical discussion about the nature of the self or selves as distinct from identity is also outside the scope of this thesis. The terms self and identity will be used interchangeably throughout this discussion.

While theorists from different philosophical and research traditions offer various definitions and approaches to understanding identity, Kroger (2004, 2007) and Craib (1998) note most contemporary theories elaborate on Erikson's original ideas through five primary lenses; historical, structural, socio-cultural, narrative, and psychosocial. Each of these theories has evolved and adapted as they have been critiqued and embraced throughout modern, romantic, post modern or post structural paradigms. According to Kroger (2007), historical perspectives stress the historical relativity of concern with identity; though historical factors are important, critics highlight this lens does little to explain individual differences in identity. Structural lenses follow the work of known theorist Piaget, focusing less on context, and honing in on internal, predictable, developmental structures that enable individuals to accommodate and interpret life events. Socio-cultural paradigms highlight societal and contextual possibilities and limitations surrounding identity development. Similar to the historical perspective, structural paradigms are

critiqued for their difficulty explaining individual differences in identity. Narrative approaches consider individual identity experiences versus generalized identity principles. These perspectives look at the 'whole person', paying attention to how internal processes and societal messages are integrated into one's life story; the self is created through the telling of the story. Finally psychosocial frameworks (most notably Erikson, 1963 and Marcia, 1966 as cited by Côté & Levine, 2002) attempt to consider both individual internal biological and psychological influences and societal demands. This framework has arguably been the most influential in identity research and underpins many contemporary programs and perspectives (Kroger, 2007).

Developmental theorist Erik Erikson is widely recognized as a pioneer in identity research. His ideas profoundly influence current research studies and theories exploring identity (Craib, 1998; Kroger, 2004, 2007). Erikson perceived identity formation as an evolving, epigenetic, universal task of development; continuing through the life cycle though particularly important to 'master' during the adolescent years (Erikson, 1968). The adolescent process was thought to be "conclusively complete only when the individual has subordinated his childhood identifications to a new kind of identification, achieved in absorbing sociability and in competitive apprenticeship with and among age mates" (p. 155). Although identity formation was perceived to continue across the life span, later wholeness and psychological well being was believed to be largely influenced by achieving a firm sense of identity in adolescence. The inability to achieve this identity has been pathologically linked to a variety of psychological afflictions (Erikson).

Drawing on the work of Freud, Erikson's theories have a psychoanalytical tone, conceptualizing identity as "involving a subjective feeling of self-sameness and continuity over time" (Kroger, 2007, p. 7). Erikson and present day traditional psychologists, conceived identity

as an internal or intra-psychic structure, residing within an individual; fixed, formed and 'owned' by that individual (Côté & Levine, 2002). Within this framework identity is developed through both a conscious and unconscious process, shaped by an individual's psychological needs, biological characteristics and the cultural milieu in which one resides. Erikson was one of the first to recognize the psychosocial nature of identity, positing that in addition to this feeling of self-sameness, identity is composed of a consolidation of relationships, past and present, life experiences and personal history, and the presiding social and cultural context (Erikson, 1968, Kroger, 2007).

Identity formation has been viewed as a reciprocal process between the psychological interior of the individual and her/his socio-cultural context. I would be remiss not to mention the work of developmental psychologist Urie Bronfenbrenner's (1979) ecological theory of development, a fundamental philosophy within Child and Youth Care. He also emphasizes the role of cultural contexts in understanding individual and identity development, stressing the importance of the interactions between developing individuals and all layers of their surrounding environments. These contexts serve to support or constrict developmental trajectories through interaction processes. Through modeling certain roles as acceptable and desirable, and responding and validating young persons' expression of new behaviours and identities, individuals and social structures inform identity processes. The young person, in response, affirms or denies a cultural connection; maintaining allegiance and loyalty or increasing separation. A sense of self arises from the capacity to shape these influences into a coherent whole, one that is unique, socially acceptable, and linked to the past.

Erikson identified four primary experiences within the identify formation process; identity crisis, foreclosure, negative identity and moratorium. These have been elaborated on by

many academics, the most notable being Marcia (1964, 1966, as cited by Côté & Levine, 2002). Marcia's identity statuses include; identity diffusion, identity foreclosure, identity moratorium, and identity achievement and have been empirically validated as distinct modes of dealing with identity issues and serve as the dominate framework in current studies researching adolescent identity (Côté & Levine, 2002). Kroger's (2004) review of the literature revealed the publication of more than 500 studies drawing on Erickson's paradigm. Various quantitative tools and structured qualitative interviews have been created to measure one's internal state of meaning construction, ego development and emergent identity to determine identity statuses, factors influencing achieving said statuses (peer and family relationships, attachment, ethnicity, temperament, education, work, etc.), and ways to support optimal identity formation. Kruger (2004) notes that such studies have indicated a sense of feeling *different* from one's peers and how individuals integrate this feeling of difference into their identity forms the most common issues in identity development among adolescents.

Identity and Adolescent Development

Adolescence is frequently divided into three stages; early, middle and late, characterized by changing biological, psychological, sociological developments and expanded socio-cultural roles and expectations. Regardless of the framework one utilizes to study identity, theorists accept that the process of identity development occurs throughout the lifetime. However adolescence is seen as the most important and unique period of identity exploration. Childhood developmental experiences evolve to profoundly influence an adolescent's identity construction process but young people do not possess the prerequisite physiological and mental maturation and social responsibility necessary to consciously engage in the tasks of identity formation before this time. For Erikson, identity development is the inevitable fifth psychosocial stage of

development. The culmination of the first four stages influence how this stage is experienced and the process of identity development influences the next three stages, setting the groundwork for subsequent identity and meaning making processes in later adulthood (Erikson, 1968).

Young people are faced with the task of adjusting to vast physical and emotional changes, as well as external expectations and reactions to their burgeoning young adulthood, while balancing their own expectations and hopes. Young people negotiate a transition away from childhood and experience new pressures from parents, school, and peer group, while at the same time struggle to hold on to and create a coherent sense of self – acceptable to themselves and others. It is a significant and often troubling period of development. They strive to answer the pivotal question ‘who am I?’ while experimenting through various interests and identities, and trying to discern vocational directions in critical and unique ways. It is important to note the vocational tie to identity is experienced differently among individuals given the current global market, and discriminatory, marginalizing and oppressive societal practices within the social milieu – factors frequently overlooked in traditional identity theories (Kroger, 2007).

By late adolescence most young women have reached the end of the observable physical changes of puberty; their bodies have assumed their adult contours and proportions. They have typically entered a new phase of quasi-adult responsibility, however unique psychosocial and cognitive developments remain. It is interesting to note this period of development is typically seen, anticipated and experienced as one of the physically healthiest period of development across the life span with lower incidences of hospital visits, days home sick, and increased vitality when compared with other stages (Kruger, 2007). This is one of many factors that make studying the relationship between illness and identity among this age group particularly pertinent.

Drawing on Erikson's work, this stage is thought to involve two important identity related psychosocial challenges; the process of separation or individuation and the process of forming new levels of intimacy. The two are interconnected since the process of developing an autonomous self facilitates a renegotiation of one's relationship with caregivers and forming new levels of intimacy in other relationships (Kruger, 2007). However it is important to note that intimacy status has typically been measured in regards to commitment to a heterosexual relationship. Intimacy in heterosexual, bisexual or transgendered relationships has not received much attention, nor has relationships with alternate forms of sexual involvement perhaps perpetuating a heteronormative view of intimacy/identity development. Much of the literature exploring the impact of chronic illness on adolescents focuses on the process of individuation or actualization, citing the difficulties adolescents face separating from caregivers as their illness restrictions or treatment regimens places them in a position of prolonged dependency (Jessup & Parkinson, 2010).

Developmental psychologists note vast differences between adolescents' cognitive development throughout late adolescence, but this period is typically marked by a shift from a sense of certainty regarding objective knowledge to an appreciation of the social construction of reality, i.e. moving into a stage of formal operational thinking (Kroger, 2007). With increased cognitive skills adolescents are able to engage in diverse thought patterns regarding identity issues such as 'who am I' as distinct from important relationships.

With increased cognitive skills, adolescents are able to engage in abstract thought and reason from a more autonomous perspective and also become more aware of societal pressures, expectations, rules and norms. As discussed in the previous section, identity theorists differ in their level of attention to societal forces, but virtually all recognize that culture influences the

identity process. As Baumeister and Muraven (1996, as cited by Kruger 2007) argue, individuals modify their identities according to what will best enable them to live successfully in a particular context. Social contexts both hinder and promote diverse processes of identity formation in how they welcome or restrict young people's access to situations and events.

Beyond Erikson

While acknowledging the valuable contribution of Erikson's work several theorists recognize the limitations and sexism within his theories and traditional understandings of identity; namely, the Ethnocentric, male, Euro-Western point of view. Prominent postmodern, constructionist theorists such as Gergen (2009), feminist scholars such as Josselson (1996) and Gilligan (1982) and sociologists Côté and Levine (2002; Kruger, 2007) challenge theorists to look beyond the internal psyche to consider how power dynamics, and context; particularly significant relationships and cultural limitations/possibilities, affect identity formation.

Gergen's (2009) social constructionist view posits that identity is best viewed within the intricate web of complex social relationships, rather than existing solely within a person. He perceives the notion of a coherent, stable identity as outdated and nearly impossible to attain given the multiplicity of relationships and social realities individuals experience in contemporary Western society. Rather than pathologizing individuals who do not form a consistent core, fluid or fragmented identities are normalized as an inevitable result of engaging with the plethora of values and opportunities afforded by contemporary socio-cultural contexts (Kruger, 2004). Unity of one's experience of the self is a reflection of unity across social experiences, rather than an internal stable or constant 'core' (Gergen, 2009). Within this framework the multiple nature of the self creates a plethora of possibilities (within cultural or structural limits) for individuals to "recreate" oneself according to the situations in which one is placed (Craib, 1998). Rather than

perceiving multiple identities as destabilizing and problematic as some critics propose (Côté & Levine, 2002), the possibilities facilitated by this fluid and relational conceptualizations of identity are embraced for the potential freedom afforded. Viewed as ‘manic’ by some and optimistic by others, this view is contested within the literature but is gaining momentum.

Similarly, Slugoski and Ginsburg (as cited by Kruger, 2007) argue notions of identity ‘crisis’ and ‘commitment’ should not be viewed as private intra-psychic experiences, rather they are “culturally sanctioned modes of discourse that allow individuals to ascribe to their actions some degree of rationality or meaning” (p. 20). Yoder (2000) has expanded on the role of external forces, and describes how societal barriers of racism, ableism, sexism, ageism, oppression, etc., limit identity options available and control or constrict processes of meaning making and identity development. While traditional theories acknowledge the role of context and relationships, much focus remains on the individual's agency and internal processing in engaging in the process of identity formation.

Narrative approaches expand traditional paradigms by emphasizing the importance of understanding the whole person in context, rather than understanding isolated values, accomplishments or personality characteristics. This framework considers how one integrates experiences and creates meaning through constructing and telling a life story (Kruger, 2007). As life stories are told, the self is constructed. It is the narration of the life story that provides coherence and facilitates meaning making and a sense of identity. The narrative resources available to tell life stories however are restricted; cultural scripts, power relations and additional contextual factors inform the kind of scripts available and influence how individuals narrate and see themselves (Frank, 2010; Gergen, 2009). As stories are told they are received, the manner in which they are received adds another layer of possibility and hindrance to how these stories are

internalized and the self is perceived (Frank, 2009). The concept of narrative identity expands traditional notions of identity recognizing the relational and contextual influence in the construction (versus formation) of identity.

Identity within this study is theorized from a social constructionist and narrative perspective. Of interest and concern is how individuals make meaning of their experiences. Attention is paid to how social and interpersonal dimensions of having CF influence participants' sense of self. This approach has garnered less attention in the literature exploring experiences of chronic illness in general and CF in particular, where identity is typically defined by internal and cognitive characteristics. Within the present framework, eliciting narratives of personal experience is seen as a particularly valuable method to make the subjective and private experience known to another.

Narrative Turn

Human beings have been called 'storied people' throughout time. Holloway and Freshwater (2007b) aptly state that wherever you find humans you will find stories. Voicing and constructing stories of experience provides a primary avenue for meaning making, both for the storyteller and the listener (Frank, 1995; Mahoney, 2003). The stories "that we tell ourselves about ourselves become the fabric of our existence and the literal meanings of our lives" (Mahoney, 2003, p. 101). Humans define themselves and their experiences through narratives and are in turn shaped by the meta-narratives of the broader cultural and temporal climate. These stories are continually created, heard and silenced in the context of illness as individuals strive to make sense of body and symptom experiences.

Recognizing this, personal narratives have received greater attention in medical matters, particularly in understanding chronic illness (Bury, 2001) and narrative inquiries exploring the

subjective experience of illness have become increasingly common throughout the literature (Holloway & Freshwater, 2007a). Arthur Kleinman (1988), a medical anthropologist, recognized the importance of listening to and facilitating the telling of illness narratives as a means of obtaining valid and valuable information about illness experiences. He encouraged practitioners to move beyond self report forms or standardized interviews, or biomedical testing, to consider the narratives individuals tell about their illness experiences in addition to bodily pain and psychological symptoms. How individuals make sense of their experiences provides an important window into the inner hurt, pain and triumph of living with an illness, making the subjective experience more knowable to the outsider.

Narratives are valuable sources of information in and of themselves, but they carry an additional dynamic value through the act of telling and through the art of listening; empowering or therapeutic for the narrator, and deepening the listeners' empathy and understanding of the holistic lived experience. Frank (1995) writes extensively about the particular meaning of story telling in the context of illness as “[those who have been, or are, ill] need to become storytellers to recover the voices that illness and its treatment often take away” (p. xii). The narratives individuals tell, hear, and create about their illness experiences - illness narratives, continually construct and are reconstructed by their sense of self. Questions of identity and self are intricately linked to these constructed narratives, as Holloway and Freshwater (2007a) state, we "make or create ourselves through narrative" (p. 705).

Frank (1995) highlights various functions and types of illness stories available for individuals to tell and hear about their subjective experiences. Language and culture limitations hinder the expression of narratives but the act of telling stories can potentially challenge oppressive stereotypes, and reshape identities. Frank's (2010) later writing explores the "work"

that stories do and the power of thinking *with* stories versus decoding stories to understand meaning without imposing personal assumptions and assessments. The stories told are an entry point into the experience; the experience of identity and illness.

Frank's (1995) theories have been utilized in previous studies of illness narratives (Sparkes, 2004; Thomas-MacLean, 2003; Whitehead, 2005) but these approaches did not specifically consider the experiences of youth. When youth were included, their age was not considered a distinguishing feature and the results were clustered. My study explores the connection between illness narratives of young women with CF and their identity, utilizing current knowledge of illness experiences and Frank's (2010) socio-narratology framework to understand and explore participants' meanings.

While exploring narratives, I am aware of the debates and contested view of illness narratives among members of the research community. The primary concerns appear three fold; the fundamental nature of narrative data, methods of analysis, and ethics. According to Thomas (2010), critics such as Atkinson (1997, as cited by Thomas) warn against privileging these narratives as somehow more transparent, or real, reflecting a unique 'hyper-authenticity' and thus minimizing the socially constructed nature of all knowledge. Aligning myself with Thomas (2010) and Frank (2000), I believe illness narratives told by those living with illness differ significantly from those told by practitioners; the former is arguably more *unique* but both are valuable forms of knowledge serving very different social functions.

Critics suggest thinkers such as Arthur Frank and Arthur Kleinman approach illness narratives with a "misplaced sentimentality and romantic vision" (Thomas, 2010, p. 650) questioning the ethics of holding a therapeutic goal of individual empowerment alongside methodology. Proponents of narrative inquiry respond to this rebuttal with a call to "mutually

implicate” the scholarly and therapeutic, utilize stories as a means to be with and think alongside others, and draw the private experiences of suffering into the public sphere. Throughout this study, my practices of reflexivity will enable me to resist engaging in sentimentality or romanticism, and listen *with* the stories shared by the participants (Frank, 2010).

Chapter 3: Methodology

In this chapter I introduce key elements of my research methodology by drawing on the work of Caelli, Ray and Mill (2003). These authors identify several steps for conducting 'good' qualitative research which include: aligning my inquiry with existing philosophical paradigms of qualitative research; discussing my theoretical orientation; locating myself as the researcher; delineating the research process; and describing steps taken to ensure rigor. I start by situating my study within the field of 'generic' qualitative research, while acknowledging its connection to narrative inquiry traditions. My theoretical orientation and positionality are explicitly explored as they have shaped the lens I brought to every step of this research process. I outline the procedural details of my research to ensure transparency and authenticity in the gathering and interpreting of participant accounts; a crucial component of ensuring rigor (Padgett, 2008). Together these foci add to the credibility and authenticity of my research (Kirby, Greaves, & Reid, 2006).

Generic Qualitative Research

Qualitative inquiry, a field of research in its own right, cuts across multiple disciplines and subjects to offer rich descriptions and interpretations of participants' lived experiences in a way quantitative studies cannot. The plethora of methodologies and methods embraced by qualitative researchers and the language used to describe these studies can create a confused picture of qualitative research approaches. Despite these differences, Denzin and Lincoln (2003) stress qualitative research can be generically defined as: "a situated activity, that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible" (p. 4). While following predetermined techniques and situating the inquiry in philosophic frameworks are important elements of credible research, Caelli et al. (2003) highlight an increase in the use of 'generic' qualitative research, especially among graduate

students. The authors suggest this trend may be influenced by students' limited time to develop an in-depth understanding of qualitative philosophical frameworks, or engage in "theoretically or methodologically sophisticated studies (p. 2)". This does not negate the necessity of engaging in research that is thoughtful and rigorous, but acknowledges the difficulty and predicament common among graduate students like me.

Generic research "which is not guided by an explicit or established set of philosophic assumptions in the form of one of the known qualitative methodologies" (Caelli et al., 2003, p. 2) deviates dramatically from the confines of traditional quantitative inquiries and differs slightly from classic qualitative approaches; such as ethnographic, phenomenological or grounded theory. However, it has been argued that this deviation does not make these approaches any less valuable or credible forms of research. To ensure trustworthiness and a 'good' generic study, researchers must explicitly state their assumptions, position, methodology, approach to rigor and analytic lens (Caelli et al.). While my study is strongly connected to and influenced by narrative inquiry, such as Arthur Frank's (2010) dialogical narrative analysis, it falls within the 'generic qualitative research' paradigm.

Narrative Inquiry

There are multiple approaches to narrative research. While fundamental philosophical tenets are shared, there is great variation between individual narrative studies; each researcher utilizes particular aspects of narrative paradigms to best explore their specific research question. Despite this diversity, narrative inquiry is frequently utilized by researchers in the fields of health and social sciences because of its powerful ability to elicit rich stories of experience, and the meanings individuals derive and ascribe to these experiences (Holloway & Freshwater, 2007b). Suffering and pain remain largely private, subjective, embodied experiences that are difficult to

express to another and complicated for the other to understand. They are best explored through research paradigms, such as narrative inquiry, that allow the richly detailed and nuanced experience to be voiced.

According to Connelly and Clandinin (1990) narrative inquiry operates on the assumption that humans lead “storied lives”; that creating and telling stories about individual and shared experiences is a fundamental component of human existence. As Holloway and Freshwater (2007a) state: “wherever you find humans you will also find stories” (p. 703). This research paradigm does not search for an objective or unbiased truth, but privileges subjectivity and positionality (Riessman, 2003). The 'truth' sought by researchers is an expression of participants' subjective experiences and the meaning created from these experiences. No two experiences or recollections of experiences are the same thus individual understanding of these experiences remains paramount.

This approach is typically aligned with constructionist, post-modern paradigms that view knowledge as constructed and bound in a particular social, cultural and temporal context (Denzin & Lincoln, 2003). Realist or positivist epistemological approaches underpinning traditional research paradigms typically view reality and truth as something 'out there' awaiting discovery. The social constructionist perspective however, highlights the co-constructed nature of knowledge, truth and reality, rejecting the notion that an ultimate 'truth' can be discovered (Gergen, 2009; White, 2007). These assumptions facilitate the examination of "the ways in which humans construct their world" (Holloway & Freshwater, 2007b, p. 15), and how the stories "people tell to and about themselves... construct who they are" (p. 19). Identities are intimately tied to personal and cultural narratives, as Holloway and Freshwater (2007a) state “we make or create ourselves through narrative” (p. 705).

Methods of narrative inquiry vary across disciplines, but 'narrative' is consistently conceived as both the focus of study and the means of generating 'data' to study. Stories are valued both for content and form; what is or is not said is just as important as *how* it is said (Riessman, 2003). Narrative researchers do not search for a generalized source of knowledge but recognize the uniqueness of the participants' experiences embedded in a broader social, cultural and temporal context. Themes and similarities within the narratives are important, but as Frank (2010) states “stories are valuable for understanding the experience... not because they are typical, but rather because they are *vivid*... Each person’s story can remain unique while being representative in that uniqueness” (p. 116). I am not searching for a universal ‘truth’ of experiences to be generalized to all young women with CF, rather I am striving to accurately represent the richly descriptive accounts of participants’ lived experiences.

Sociologist Arthur Frank, has written extensively about the function and form of stories. His earlier work (Frank, 1995) presented various typologies as analytical tools to think about illness narratives and has expanded to broadly consider the *capacity* of stories (Frank, 2010). Frank encourages listeners (lay persons and researchers) to let stories breathe and hear the relational activity in stories. He posits that “people tell stories to reaffirm, possibly to create and possibly to redirect the relationship within which the story is told... stories as acts of telling are relationships” (Frank, 2000, p. 254). He (Frank, 2010) theorizes a symbiotic relationship between individuals and stories where people and stories evolve alongside one another; co-shaping one another as they unfold, continually moving through time and space. Both his earlier suggestions of typologies and later exploration of the *work* of stories influence this thesis.

Frank (2010) proposes a dialogical framework to study accounts shared by participants, not as a tool for professionals to “decode and classify” (Frank, 1998, p. 200), but as a pathway to

join the illness experience. The stories told are entry points into the experience of identity and illness. They become 'listening devices' that work and breathe to enable listeners to think *with* rather than decode and impose assumptions and assessments. In Frank's (2010) words,

“analysis is dialogical not only because [it] respects the narrative arc of the whole story, but also because [it] does not finalize [participants] by imposing a psychosocial evaluation... For example... when storytelling is relegated to being a form of ‘coping’ dialogue suffocates, because the analyst takes the position of an external evaluator of another person’s success or failure” (p. 177).

Much of the literature exploring experiences of adolescents and young adults living with chronic illness focuses on coping, or adherence, arguably imposing a psychosocial evaluation rather than exploring deeper meanings of experiences. Frank's (2010) perspective presents a refreshing alternative. Using experiential stories as ‘listening devices’ and creating a pathway into the experience offers persons living with illness, and the people surrounding them, a chance to better understand the nuanced, subjective and contextualized illness experience (Frank, 2010). It is important to remember that while richly subjective, these stories amplify some voices, while silencing others, reflecting particular collective and individual socio-cultural histories and preferences. As Whitehead (2005) states “the narrativised reconstruction is concerned with gaining meaning and importance of the illness by placing it within the context of one’s own life and reconstructing the narrative of the self” (p. 2236). The retelling and restructuring of these narratives remains central, and provides a means to “re-establish the relationship between the self, the world and our bodies” (Whitehead, p. 2236). This framework of dialogical narrative analysis (Frank, 2010) will be further outlined in the section titled “Approach to Analysis”.

The embodied quality of stories is also pertinent as “they are told not just about the body, but through it” (Frank, 1995, p. 3). Furthermore, “people certainly talk about their bodies in illness stories; [but] what is harder to hear in the story is the body creating the person” (p. 27).

Bodies are changed through illness and body-self unity is disrupted as assumptions of body health, beauty, reliability and function are challenged. Living in a time and culture where youth, thinness, fitness and sexuality, are unspoken assumptions of 'health' I listened for the stories these young women tell about their relationships with their bodies, and the impact on their ongoing identity construction.

Theoretical Orientation

The ontological and epistemological position I bring to this study is informed by a social constructionist perspective and is particularly influenced by thinkers such as Gergen (2009; 2010). This perspective guides many of my beliefs about the world and how it can be understood, thus it informs the lens through which I view participants' accounts (Denzin & Lincoln, 2003). It privileges subjectivity, and in keeping with a post-modern ideology suggests that humans construct knowledge and meaning from their interactions and relationships with objects and others in the world. People are cognitively proactive and continuously engage in ordering processes, constructing narratives and stories in attempts to create meaning and knowledge (Gergen, 2009). These stories are co-constructed within the bounds of relationships and cultural norms and can only be understood within this context. Truth and knowledge are not abstract concepts to be discovered and known; rather they are co-constructed, embedded in particular cultural and temporal contexts.

A social constructionist perspective also informs my perspective of the "self". While an in-depth discussion about the nature of the self is beyond the parameters of this thesis, it is important to acknowledge the breadth and depth of literature and ongoing tension that exists regarding the nature of the 'self' and identity (Gergen, 2009; Gergen 2010; Hansen, 2009). As discussed in my literature review, the 'self' has traditionally been perceived as an internal,

consolidated, stable structure, which can be discovered and accurately represented with language (Hansen, 2009). While this perspective has offered valuable information and perspectives, and continues to inform versions of modernist psychology, it remains challenged by many critical and post-modern theorists. Post-modern challenges to positivist epistemological assumptions about the discoverable nature of truth and knowledge extend to challenge assumptions about the nature of the self. Just as knowledge and truth are conceived as co-constructed realities in this paradigm, the self is viewed similarly. Rather than an internally 'discoverable' and stable self, post-modern theorists suggest the self may be more aptly conceived as co-constructed and relationally created, challenging the positive assumptions underpinning mainstream perceptions of the self.

Aligning myself with social constructionist perspectives, in this thesis I question some of the mainstream assumptions regarding the self. Positioning my work within a social constructionist framework, my hope is to contribute to the literature proposing a more fluid, relational and unfolding interpretation of the self, (Gergen, 2010; Hansen, 2009) specifically within the literature exploring experiences of young people with chronic illness where this perspective has not yet been fully explored or utilized. I start from the premise that selves are constantly in motion, continually flowing through relational processes where individuals construct narratives about experiences and selves and then share these stories with others. These interactions with others create meaning and facilitate a continual reconstruction of sense of self and identity (Gergen, 2010; Holloway & Freshwater, 2007a; Holloway & Freshwater, 2007b; Singer, 2004). Identities are created and reinforced throughout the telling and retelling of these narratives, thus constructing an identity is never final but a life long, dynamic, interpersonal, interactional and relational process.

Positioning Myself as the Researcher

In addition to exploring my theoretical orientation, it is important to situate myself, personally and professionally, in this study. This position is not fixed or static but the history and context I carry with me informs my engagement in the research process. Researchers' curiosity, choices and interest in a particular topic are informed by passion, experience and caring, inevitably connecting researchers to the topic in a non-neutral manner (Kirby, et al., 2006; Pinnegar and Daynes, 2007). I intentionally identify my interest and connection to the topic with the hope of dismissing the myth of objectivity or neutrality and increasing my transparency and authenticity. I come to this study as a cisgendered, Caucasian female, with a standpoint forged by my experiences as both an insider and outsider to illness experiences. I am an insider because having lived through cancer as a young woman (19 years old) I carry my own illness narrative that continuously shifts from foreground to background constructing my sense of self and body-self connection. This insider position brings particular knowledge, insight, and privilege. I remain an outsider however, to the experiences of living with CF. As a youth with CF reminded me, cancer wreaks havoc and then goes away. CF is always present, maintaining a constant presence, threat and opportunity; I have no insider experience of this reality. This insider/outsider position is constantly negotiated through my interactions with participants and the data in this research process (Kirby, et al., 2006).

I come to this study with years of professional experience as a Child Life Specialist. I have worked with children and youth with complex acute and chronic medical needs for the last decade and have heard powerful accounts from courageous individuals. I have heard 'success stories' and stories of 'failed' interventions. I have also witnessed silences, medicalized stories, stories of treatments, procedures, tests and appointments, numbers and data. Among the children

and youth I have worked with, details of diagnosis, dates and symptoms were often recalled with precision, but little connection was made to how their sense of self was impacted and perceived through these events. As selves are “perpetually recreated in stories” (Frank, 1995, p. 53), exploring how youth make meaning from their experiences of living with CF: constructing and reconstructing a sense of self is a particularly meaningful way to fill this gap. Additionally, I have known young people with CF, and have witnessed frustration and isolation, and experiences of being misunderstood while living with a ‘lesser known’ disease. I hope that contributing to the literature may decrease some of this isolation.

I also bring strength based and developmental lenses to this study, recognizing the unique challenges and strengths within young people, believing they offer valuable and reliable contributions to the literature. This orientation leads me to see participants as active members of the research team, thus my approach was tailored to facilitate the involvement of young people rather than talking with their family or health care team.

Delineating the Research Process

Participant recruitment. The joint Human Research Ethics Board (HERB) at UVIC and VIHA approved all recruitment strategies and research design prior to any participant recruitment and contact. I received ethics approval to recruit up to six participants for this study through purposive sampling practices. Three young women who met eligibility requirements replied and requested to participate in the study. Participant eligibility parameters required that participants identify as female, between the ages of 16 and 22, reside in Victoria, BC, and not be hospitalized at the time of interviews. Current health status was not considered in the eligibility criterion, as this is a subjective assessment and difficult to predict. Age of diagnosis was also not considered in sampling restrictions since 60% of people with CF are diagnosed within the first year of life, and 10% by 10 years of age (Cystic Fibrosis Canada, 2013). Participants were given

a pseudonym for this study, and all efforts were taken to minimize identifying information to ensure confidentiality and anonymity.

I consulted the medical doctor, social worker and nurse clinician working at the Victoria outpatient Paediatric Cystic Fibrosis Clinic, and Victoria Adult Cystic Fibrosis Clinic, gaining permission and assistance to recruit participants through their programs. The Victoria Paediatric clinic did not have potential participants who fit my criteria so recruitment packages were mailed to potential participants by the nurse clinician at the adult clinic. I also collaborated with the President of the Cystic Fibrosis Canada, Victoria Chapter, who posted my recruitment poster on the Chapter's Facebook page. The nurse clinician sent one email to potential participants after the packages were mailed, though the three participants each contacted me prior to this reminder email, expressing interest and excitement to participate. It was an honour to speak with these young women, their candor, wit and courage was evident and appreciated throughout the interview process.

Interview process. The material obtained through narrative interviews is often referred to as 'data'. However the term 'data' is derived from quantitative traditions and does not fit with the language of experience that qualitative inquiry elicits (Holloway & Freshwater, 2007b). I have chosen to use the term 'accounts'. These accounts were elicited through two semi-structured, one-to-one interviews with each participant for a total of six interviews. Interviews were conducted at participants' homes or via Skype. Interviews are readily used and recognized in narrative research as a powerful and effective means to explore experiences and meanings attached (Holloway & Freshwater, 2007b; Kirby, et al., 2006). The term interview however, may be misleading. Rather than an exchange of questions and answers, a flowing conversation is a

more accurate description of our interaction (Holloway & Freshwater, 2007b; Newbury & Hoskins, 2010a).

I spoke with each participant twice over a two-week period, each exchange lasted between one and one and a half hours. Keeping my research questions in mind, the initial conversation focused on establishing rapport and eliciting accounts of their lived past, present and future experiences as they contributed to their sense of self; important people in their lives, crucial events, and perceptions of how their experience of illness impacts their sense of self and daily life (see 'interview questions' in Appendix A). Conversations were video recorded and I took notes during and after each interview with my initial reactions, observations and hunches. I chose to video record rather than just audio so that I could attend to *how* participants were speaking about their experiences rather than just what was being said (Holloway & Freshwater, 2007b; Riessman, 1990). Writing notes after the interviews was a reflexivity practice embraced throughout the research process to minimize my biases and assumptions (Kirby, et al., 2006).

The active role of the researcher as a co-constructer of knowledge both as a listener and through engagement with the participants is widely recognized and documented in the social constructionist literature (Frank, 2009; Koro-Ljungerb, 2008; Riessman, 1990). As Riessman (1990) stresses, it is important to remember the non-neutrality of researcher presence; "a particular self is constituted through these [interviews], occasioned by the presence of a listener, her questions and comments" (p.1195). The relational process of the research conversation is another site of co-constructed meaning. Throughout the conversations I maintained a curious, 'not knowing' stance (Anderson, 2005) engaging in interactive, dialogical, generative conversation that was much less researcher controlled allowing participants to follow their own

agenda rather than be constrained by mine (Holloway & Freshwater, 2007a; Koro-Ljungerb, 2008).

It is important to acknowledge the potential limitations of language to capture the depth of human experience, as Leitch (2007) accurately states; "[although] language reveals, it may also conceal" (p. 552). There is growing support for the use of arts-based methods to complement spoken accounts and facilitate 'multi-narratives' potentially constrained by the limitations of verbal language, thus increasing the depth of understanding and richness of expression (Bach, 2001; Estrella & Forinash, 2007; Harrison, 2002; Thompson, et al., 2008). Recognizing this, after the first conversation I asked participants to choose up to six photographs, either existing photographs or shooting new images, in response to the question 'Who am I?'. My hope was to give participants a new and additional opportunity to express the complex ways they make meaning of themselves and their experiences, perhaps leaning on metaphors and symbolism to move "beyond the concrete aspects of life" (Newbury & Hoskins, 2010a, p. 172). The use of metaphor and imagery to assist in the expression, discussion and understanding of meaning making processes has been a well-documented component of narrative inquiry. Photography has frequently been utilized as an effective tool in this process (Newbury & Hoskins, 2010b; Thompson et al., 2008). As Newbury and Hoskins (2010a) posit, the addition of image and metaphor can increase the breadth and depth of learning by "accessing nuanced and less calculated ideas...and incorporating societal and contextual aspects of experiencing the world" (p. 168). Additionally, the interactive, participatory nature of arts based research methods are widely recognized as effective and appropriate means of engaging with young people, and flattening the hierarchical researcher-participant relationship (Alderson, 2005; Docherty & Sandelowski, 1999).

The second interview was scheduled to take place within 10 days following the initial interview. All participants chose to meet within this time frame indicating this was ample time to reflect on the question and choose photographs. In the days between the interviews I transcribed the initial interview word for word, and then reviewed both the written transcript and audio/visual recording of the meeting. This review highlighted tentative initial themes and provided an opportunity to note areas needing increased participant description, rather than relying solely on researcher interpretation. This process also served as a practice of researcher reflexivity and self-awareness, as I was able to discuss my initial assumptions and reflections with participants, minimizing my assumptions and biases (Kirby et al., 2006).

I began the second interview with each participant asking about their reaction following the initial interview, checking out the impact of our conversation. All participants felt the initial interview had impacted them positively, as it gave them opportunity to think about their experiences differently and they were confident they had accurately shared relevant experiences and information. When I sought more information or clarified my understanding each responded favourably, appearing to appreciate the attempt to minimize assumptions and represent their experiences faithfully. During this interview participants selected one photograph at a time to discuss. We looked at the picture together and conversed about how the photo responded to the question 'who am I?'. Each participant chose between four and six pictures and the interview exploring these photos lasted between one and one and a half hours. I chose to highlight just one photograph from each participant in the body of this thesis, however excerpts from both the initial conversations and dialogue exploring the photographs is integrated in the discussion chapter. Choosing the photograph was difficult, but I picked the one that seemed to elicit the

most animation, dialogue and excitement from the participants, and that best represented or symbolized prominent patterns within the accounts

The three participants approached the photographic component of this study differently. One energetically dove in citing a "love of imagery and symbolism", submitting deeply metaphorical pictures. The second approached the task with equal willingness but relied on concrete images reflecting hobbies, interests and important people. However, through conversation she was able to unpack layers of symbolic significance, exploring the meaning of being a student or maintaining a particular role in the family. The third expressed hesitation towards the photography, feeling confusion about what to submit and a struggle to "depict the experiences in an image". The three participants each had three different reactions to the research process, demonstrating the difficulty of finding one method of 'data' collection comfortable or meaningful for all participants, and the value of embracing multiple methods.

Approach to analysis. Congruent with narrative analysis approaches, my approach to analysis was a continuous, rich and time intensive process. Perceiving the accounts as 'listening devices' (Frank, 2010), I listened and watched the video recordings numerous times, taking time to "*live with the data, getting comfortable with what it says... and discover the more holistic understandings*" (Kirby, et al., 2006, p. 221). As mentioned above, after the initial interview, I watched the video recording once, and transcribed the conversation word for word. I then read through the transcript noting potential themes in the individual accounts. Following the second interview I watched the video recording once, looking at the photographs alongside the video, then transcribed the conversation word for word. Then I read the transcription and again reviewed the photographs. After watching, transcribing and reading each individual account I read across transcripts from both interviews looking for emerging themes between conversations.

Finally, I read across participant interviews, looking for shared and divergent themes and experiences (Holloway & Freshwater, 2007b). I read and analyzed the transcripts holistically and line by line to hear general and specific experiences, paying attention to what was said and unsaid, attending to contextual nuances and subtleties of how individuals spoke their world (Riessman, 2001).

Initial key concepts were colour coded within participant narratives, similar components were grouped together and expanded as my understanding of meanings beneath and within the stories unfolded (Caelli et al., 2003). I felt a recurrent tension between reading these accounts holistically, taking the stories as a ‘whole’ while still parsing out pertinent themes. As shown in the next chapter, I have attempted to represent the accounts in their entirety rather than reducing them and dissecting them into fragments. This tension is common, according to Riessman (2003), “deciding beginnings and endings of narratives is a complex interpretive task... shaped in major ways by theoretical interests” (p. 335). I have chosen to keep the quotes written in this thesis in the voices of the participants, opting not to ‘clean up’ their pauses and slang in an effort to remain faithful to the manner in which the stories were spoken.

Many of these assumptions within my theoretical orientation have been made clear in the section exploring my theoretical orientation and positionality, however the concepts of dialogical narrative analysis must also be unpacked. These concepts have coloured the analytical lens I brought to the reading of these transcripts and guided how I engaged with the ‘data’ (Caelli et al., 2003).

Frank (2005) refuses to prescribe a rigid series of steps and rules for analysis, preferring instead practices that give stories room to *move* fluidly and offering his approach as a heuristic guide. While still highlighting patterns within and between accounts his approach differs

dramatically from traditional thematic analysis that relies on rigorous coding and analyzing processes. Much has been written about his approach to analysis, but he notes four primary components of dialogical narrative analysis, which have informed my lens. First, this process involves researcher engagement in practices of critical thinking, “refus[ing] to accept immediate, common sense understandings, while at the same time having the most profound respect for and curiosity about common sense understandings” (Frank, 2010, p. 73). Simultaneously appreciating that participants are experts about their own lives, while also recognizing and examining how a person’s understanding of the world remains somewhat blind. This opens the realm of analysis to consider broader cultural narratives surrounding illness and wellness that may influence young people’s identity construction.

Second, rather than a stagnant method, Frank (2010) proposes that analytical thought is constantly in motion, specifically flowing through dialogue. “Thought moves in dialogue, as those participating in the research are given scope to upset presuppositions of the researchers” (p. 73). This is consistent with social constructionist notions of co-constructing knowledge as opposed to pre-existing knowledge or truth to be discovered. Meaning unfolded through our conversations, as I read through the transcripts it continued to unfold and ‘breathe’. The third component is largely connected to this as the recognition that “any analysis is already interactive with what is being analyzed; that interaction is what makes it dialogical” (p.73).

Finally, the continued ‘work’ of narratives, expands beyond the confines of the research study. As Frank (2010) states the “‘method’ does its work within the time and space of some writing, and then the method fragments...[with the hope] that some parts will be recycled elsewhere, as part of a larger movement of thought” (p. 74). The work continues as thoughts move and stories are retold and selves are continually reconstructed. Research after all, is not a

“one-way transmission of information about lives, rather it is an ongoing dialogue between participants’ meanings and the meanings attributed by researchers... no one’s meaning is final and no one meaning is final” (Frank, p. 99). The work of stories is never ‘finished’, rather as Frank (2005) states, “the research report must always understand itself not as a final statement of who the research participants are, but as one move in a continuing dialogue through which those participants will continue to form themselves, as they continue to become who they may be” (p. 967). I hope this research will contribute and initiate more dialogue and new ways of thinking about the young people’s experience of illness and identity.

I also utilized components of Frank’s (1995) earlier work exploring story typologies as an analytical tool for thinking with participants’ stories. I recognize these typologies offer one of many possibilities for thinking with illness stories, so held them tentatively and in combination with Frank’s (2010) later work questioning the ‘work’ that stories have the capacity to do. Using the stories as listening devices in this manner allowed a consideration of participant's sense of what is possible, permitted and/or preferred (Frank, 2010; Holloway & Freshwater, 2007a). This was the lens I brought to my multiple levels of reading and engaging with the transcripts and ‘data’.

Rigor. Researchers emphatically agree that qualitative studies must be rigorous in order to be ‘good’ studies. However there is rich debate within the literature about what constitutes a ‘good’ and rigorous qualitative study (Caelli et al., 2003; Padgett, 2008). Some contest the very use of the work ‘rigor’, as this has quantitative roots and may not translate appropriately given the dramatically different philosophical tenets underlying qualitative and quantitative approaches. Additionally, despite similarities in qualitative approaches, many stem from fundamentally different principles, so criteria for evaluating these approaches cannot be applied

to all and must reflect these principles. Caelli et al. (2003) aptly state that; “rigor is a deeply theoretical issue, not a technical one” (p. 7). The authors continue to stress that “investigators need to ensure rigor by adhering to principles that are congruent with the assumptions for the approach they are using” (p. 8). Thus rigor is a process, and strategies for achieving rigor should be pursued at all stages of a study.

Ensuring the rigor and trustworthiness of my study has been at the forefront of my mind throughout the research process. I have demonstrated this by ensuring the approach to my inquiry is philosophically and methodologically congruent and appropriate for exploring my research questions. Many critics of qualitative research argue that the lack of generalization of research findings decreases the ‘validity’ of research findings. I align myself with other qualitative researchers (Holloway & Freshwater, 2007b; Kirby, et al., 2006; Padgett, 2008) and insist generalizability is not an appropriate goal for this research thus is an inappropriate means to establish or debate its rigor.

Holloway and Fullbrook (2001) warn that one area of difficulty is the relationship between the researcher and participant and the researcher’s ability to elicit ‘accurate’ and truthful accounts. I would like to address this two fold. Firstly, the material that I elicited was the participants’ truth as they recalled their experiences. Accounts are not valued because of their objective accuracy, rather by how truthfully they represent the participants’ experiences (Frank, 2010). Following the initial interview I clarified initial themes and potential areas of confusion with participants as a means of checking if I had accurately reflected their experience, the truth they had shared. This practice helped ensure the credibility of findings, an acknowledged practice of ensuring rigor (Holloway & Fullbrook, 2001; Padgett, 2008). Additionally,

participant accounts are reflected in the discussion holistically, not fragmented so the meaning is presented remains in context.

Secondly, I recognize that I was a co-constructor of knowledge and meaning in the interview process. I have not been a neutral party, as I have stressed by positioning myself, and my theoretical orientation within the research. During the research interviews I utilized basic counseling and rapport building skills to create a relationship conducive to the research conversations, and to minimize my influence. I wrote copious field notes following the interviews, as a means of recommended reflexivity to minimize bias and assumptions (Holloway & Freshwater, 2007b; Padgett, 2008).

A final noteworthy attempt to ensure rigor was incorporating photography into the data collection methods. This approach can be seen as a form of triangulation of methods, a recommended strategy to approach one topic from multiple angles (Padgett, 2008). Verbal language was not privileged over the symbolic or visual representation, and participants were given two opportunities to express and represent their experiences.

Transparency throughout the research process has been heralded as an important means of establishing rigor. The “trail describes in detail the decision-making processes of the researcher as well as the context and the setting, and enables readers of the research to judge its credibility, rigor and quality” (Holloway & Fullbrook, 2001, p. 548). I have been transparent throughout the process, providing detail about the study, and will present my findings truthfully and honestly; and I hope you, dear reader, will agree and attest to its credibility and truthfulness.

Limitations. This research explores and reflects the experiences of these three participants, in this moment in time. It is a very specific, localized, and the sample size is small. While valuable, there are limitations within the study that are important to discuss.

My decision to interview only three participants was influenced by the small number of potential participants living in the Victoria area, and the practical necessity of gathering a manageable amount of 'data'. Participant size does not reflect research rigor, however it is important to stress that the findings are not generalizable to a 'truth' of all young women with CF. As I have maintained throughout my inquiry, generalizability has not been an appropriate or attempted goal (Holloway & Freshwater, 2007b; Kirby, et al., 2006; Padgett, 2008), however interviewing a more diverse group of participants would have reflected greater diversity of experiences. Voices of individuals in a non-majority demographic, for example differently abled, non-Caucasian, non-heterosexual etc., remain absent.

I spoke with participants when they were enjoying a season of relatively good health. None were hospitalized, and each participant identified symptoms as 'moderate'. Conversations when symptoms were more invasive may have differed dramatically, thus this inquiry is reflective of participants' exploration at this moment in time. While vivid and credible, it cannot be generalized to the experiences of others or as a static representation of their experiences outside of this time and context.

Finally, while I incorporated photography in an attempt to bridge concrete and metaphorical representations of experience, participants were not all equally comfortable or clear about this method. While it opened up possibilities for one participant, it appeared to close doors for another, and may have hindered her from fully expressing her experiences. Since this method differed from traditional research, particularly research in the medical community, the unfamiliarity may have deterred some participants from volunteering. This demonstrates the difficulty for any researcher to find methods that 'work' and appeal to all participants.

Chapter 4: Introducing the Participants

The three participants I interviewed are in similar phases of life, they have each moved away from their home town, are attending or have recently graduated from post secondary education and are experiencing new levels of independence as they etch closer to the age of ‘adulthood’. The experiences of these young women vary dramatically, but each recognize they are in a profound and unique stage of life; particularly in regards to how they understand themselves, others and their relationship with Cystic Fibrosis. Many key concepts were shared across the narratives, but how they navigated these elements was as unique as the women themselves. This chapter introduces you to the participants, utilizing one photograph and excerpts from all of our conversations to paint a fuller picture.

“Marcie”

Marcie is a soft spoken, insightful and animated young woman living with Cystic Fibrosis. Marcie’s quiet and determined demeanor punctuated her narratives with rich purpose and perspective. When asked to take photos in response to the question ‘Who Am I?’ Marcie eagerly dove into the task, excited by the opportunity to express her experiences and thoughts with images and symbols, breaking free of the limitations of language. Throughout our interviews a number of metaphors and themes emerged that describe her sense of self, her relationship to CF and her relationship with her body.

Marcie enthusiastically discussed the following picture, adding rich imagery and depth to our conversation.



I like this one because how it represents me is like, I am kind of the quiet one you know, kind of like in the background and stuff. Like the listener, and watcher and stuff. So like in this picture it kind of represents that like, I'm watching over everything, and like picking up details and stuff like that. While others, probably like, well, they're in their conversations and everything, while I'm just like back a bit, and looking at the whole picture... they [important family and friends] don't realize what it is. Cause if they see me not you know, participating as much, but it's just me listening and observing cause I have a blast doing that, I love doing that. But they think, you know they're like, 'what's wrong with her?' Why doesn't she want to participate and everything? So then, they see it, but they don't understand that that's just my way of doing it...

Her words speak to the fundamental experience of not being known, or understood; and always needing to explain her differences. The experience of being different is known for many reasons, and is both familiar and resisted. The textures and layers of terrain and colour in this picture reminded Marcie of different components of her identity; connections to different people and experiences that continually shape her. She immediately drew a rich analogy that the dark clouds in the picture above are representative of her CF, providing a powerful framework to hold the many accounts shared.

Well, it's kind of always there, like hanging around... like I can see all this, [the other dimensions and layers in the picture] it's gorgeous right, it's beautiful... but then there is that black cloud over it. It's kind of always there but I can still see like beauty even though it is there. And sometimes it [the cloud] enhances it a bit, though if it would enhance it a bit less it would be better! [Laugh]. [But] CF does have its perks!

As clouds dynamically shift and change, subtle details are often unnoticed by the trained and untrained eye; leaving people unprepared and caught off guard by a sudden storm. In the same way Marcie has described her CF, despite planning and preparing and taking care of herself she frequently finds herself suddenly thrown by an unexpected bug or worsening symptoms resulting in hospitalization or bed ridden. There she waits for the storm to pass before she can reengage with the world, friends and family. Despite her best efforts to plan for future relationships, employment and illness disruptions, the dynamic unexpected nature of her illness thwarts all efforts to prepare, calling for flexibility and adaptability in her construction of identity and life goals.

A system of clouds can enhance a photograph immensely, changing lighting and texture of a photo, adding depth and dimension. Similarly, Marcie continually referred to her CF as a 'perk', alluding to the meaning and depth it has brought. Alongside the enhancing capability of the clouds, I imagine the dense mugginess heavy clouds can carry, entrapping people in its cool

wet embrace; both familiar and uncomfortable. This constraining embrace was felt across domains important for identity construction; employment, gender roles, romantic relationships and achieving independence. Most profoundly Marcie felt its sticky parameters as the time lines of CF, slowly shifting but creating a 'best before date' that always hovered on the sidelines.

Finally, while billowing clouds can be peaceful, they are also fierce, carrying thunderous energy waiting to be unleashed. Likewise Marcie carries in her a battling spirit, while she presents herself as a quiet observer, she also sees herself as a fighter, battling within and across multiple domains of her life.

“Rachelle”

Rachelle is a dramatic, intellectual, determined, outspoken and socially conscious young woman. She engaged in the interview with admirable forthrightness and sincerity. She thought deeply about each question before responding and appeared to enjoy the process. She eagerly dove into the photographic component, stating that choosing pictures was not difficult as images reflecting her values and personality immediately came to mind when she learned about the study. The conversations about these pictures were lively and insightful, and similar to Marcie’s experience, brought rich depth and further accentuated layers of Rachelle's unfolding identity.

The following photograph was titled ‘Flexible ‘Rachelle’’.



“One of my big things is I am pretty athletic in a lot of ways. So, I just thought [this picture] was a good way of kind of fusing, me having fun with also me being able to do physical activity...because it’s a kind of a common perception that people with cystic fibrosis can’t be very active and things like that. So I thought having a picture of me being out there doing things was a good indication of what my life is actually like... [pause] I think most important about this picture, is just showing that active side of me. I think it really is. Because I think, for um, a regular person, or I guess, not a regular, but

just a normal healthy person, this would probably be kind of a given scenario. But there is kind of this perception about CF people where, they're hooked up to oxygen and like, they have trouble walking around and or running and stuff like that. So I think showing that I do like to get out and like do things, really does break a lot of misconceptions that people would have if I initially told them that I had CF. So I think that's probably the most important thing about the picture, that it shows me being active, and enjoying myself...And despite having it, [CF] it doesn't dictate everything you do...you can uh, not let CF dictate what you're able to do to some extent. I mean eventually if you do have really bad health you are going to have to, I don't know, be confined to a wheel chair or have oxygen or something. But to a certain point in your disease you can basically tell it to go screw itself and you can do things despite the fact that, you might not feel like you're able to. And [beating it] feels pretty good...[laugh] and it's a little frustrating. Like, I kind of wish this wasn't so hard, but at the same time, when you do it, you're like okay, I can do it! So, it's not like I'm not able to do these things, it's just difficult for me."

Like Marcie, there is a ferocious fighter in Rachelle. She strives to consciously construct her identity; resisting the pressure to be narrowly defined, confined or controlled by her CF, or societal perceptions, expectations or pressures. From an early age Rachelle remembers consciously constructing an identity, interests and personality that was distinct within her family of origin, separate from her siblings, enabling her to be viewed uniquely. Difference was familiar and embraced, but she relates to numerous collective identity attributes among 'CFers' in general or her family and friend group.

Rachelle's sense of agency is strong as she actively rejects and embraces various perceptions of the woman she is becoming, proactively shaping how she will and will not be defined. She has found profound meaning in her illness, recognizing it influences who she is but stresses she will not be defined by this illness and actively resists and resents constricting labels. The flexibility beautifully depicted in her photograph shone through our conversations as she

shared accounts reflecting the construction of a dynamic identity navigating her ever changing world of illness, adulthood, difference, dependency, relationships, and gender expectations.

“Angella”

Angella is a dynamic young woman, smart and articulate, with a quick and rich sense of humour. Our conversations were full of laughter and jokes as her narratives were peppered with light and comedic anecdotes. Angella approached the photographic portion of the study hesitantly, reporting she felt 'stumped' about what pictures to include and discerning how to connect this to her identity. Despite this, she enthusiastically engaged in animated conversations as we unpacked perceptions of her unfolding identity.

Unlike the other participants, she connected components of the photographs to her CF only after we talked about the images at length. She was quite perplexed as to why she did not choose pictures that enabled her to speak about her CF and its impact on her identity more readily. She intentionally chose photos that represented her youthful vitality, zest and love of fun; "the part of my life CF has nothing to do with!"

Though Angella did not offer metaphors on her own, the picture below seems to best depict the perpetual, forward moving energy present in her narratives and unfolding identity. This photograph was taken shortly after she moved out of her parents' house, and was enjoying her 'new life', moving through a rite of passage out of adolescence; living independently, navigating new relationships, unfamiliar school responsibilities and health care needs. She expressed a practical rational perspective about life, illness, and her sense of self. Rather than entertaining regrets, worries about the future or preoccupations with the perceptions of others, she seems to appreciate each moment, always moving forward.



[This was] one of the first times where I started feeling like an adult! Because I was like oh, [family], you're here now and I don't really need you to be here, but I want you to be here... When I was showing [them] stuff, I'm like going around and was like... oh, this is where I do this... I just kind of, I just kind of realized I really settled in here, I've actually like made a lot of friends, and like know where everything is, and like I have my favourite places and stuff. Which, I only used to have here in [my home town], so it was just kind of like a realization that oh, this is like another home to me now. It was really weird, but

also awesome... There was a lot [of stress and anxiety about my CF] that was like one of the biggest I think stresses about moving. I didn't know if I was going to handle like all the stuff I was going to do... and... I didn't know, like how am I going to go from like one CF clinic to another, or order medication? Like how do I even do that? But, eventually it did work, and like I can manage it on my own, turns out! I'm sure a lot of other people don't even think about. It's like how a lot of people my age are like oh I'm just going to go back pack around Europe. And I'm like, ha, have fun! I'd have to do like 10,000 medications, I'd have to have a separate backpack for like for all my pills. Yeah... that just kind of reinforces like, oh right, this is my life.

Though she carries an embodied sense of 'being' different, having a different life, and understanding the fragility of life she does not dwell on this potential struggle. Rather, she continually embraces this uniqueness into her identity construction, proudly referencing her different attitude or perspective, intentionally not trying to fit in. Similar to Rachelle and Marcie, there is a warrior inside Angella. Though she does not dwell or over analyze situations, she fiercely fights against narrow and limiting perceptions, proving she is a competent and capable young woman, who cannot be slowed down. While discussing experiences, I could hear the practical maxim 'it is what it is' rolling under and through the accounts she shared.

It was an honour to speak with these women, and I hope the following chapter accurately portrays elements of the complex components of their relationships with themselves, others, and their illness.

Chapter 5: Findings and Discussion

The participants all shared rich and multi-layered accounts. My challenge now is to revisit my research questions in a manner that does not minimize nor reduce the experiences shared. The difficulty of subjectively determining the beginning and end of each narrative and discerning what to include and discard, (Frank, 2000; Riessman, 2003) was felt throughout the analysis process and continues now as I discuss the 'findings'. It is my hope that through introducing the participants and discussing prominent features and patterns within and across the accounts, as they relate to my research questions, I will accurately express their richly layered and diverse accounts.

In this chapter I will respond to the three research questions that guided my inquiry:

1. How is cystic fibrosis storied as part of young women's emerging identity?
2. How do young women living with cystic fibrosis narrate their relationship to their bodies?
3. What are the cultural narratives surrounding illness and wellness that appear to be shaping young women's understanding of their identity and relationship to their body?

Recognizing the fluid nature of experience and thought, it is important to note this discussion reflects participants' experiences of identity in this moment in time. Interviews conducted with them at a later date, or by another researcher, may lead to additional and divergent 'data' and meanings.

Each of the participants articulated unique experiences of self, identity, illness and health. Despite this uniqueness many key concepts, expressed and experienced differently, were shared between participants. Though the words participants used to describe the self were congruent with mainstream conceptualizations of the self (i.e. core, stable, etc), utilizing Frank's (2010) principles of dialogical narrative analysis revealed deeper meaning and highlighted the

limitations of language and commonsense understandings. The analytic process of listening, reading and re-reading the transcripts highlighted the dynamic nature of the young women's identities, revealing a construction of the self that expands beyond the limitations of the dominant discourse. It is a self 'in progress'; constantly adapting and changing according to the context, responsibilities, expectations, dreams and intensity of symptoms. Their stories of identity seem to be moving and changing, fluid and unfolding in time, rather than static or fixed.

Based on this premise, the flexible, dynamic, ever changing sense of self is given space to breathe and move. The participants resist being seen through a narrow, one-dimensional framework, stressing the layers and multiple dimensions of their identity. This dynamism is further highlighted through their "quest" to make meaning of illness experiences and live a life of purpose and happiness. The self in-progress is reflected through their embodiment of illness as a battle, pushing them to prove themselves in other areas of their lives. Flexibility is seen in their navigation of normative events and experiences such as career planning, dating, entering adulthood, and discerning gender expectations. Here they hold simultaneously conflicting and appealing ideals propagated by the mainstream cultural norms and expectations, in tension with their own timelines and goals intimately tied to their illness experiences.

Just as the narratives unfolded; multilayered and complex, this discussion is also layered and dynamic. The accounts do not easily fall within the tidy constraints of written work; the meanings within accounts inevitably overlap the boundaries of each subsection, adding texture and integrity, further representing the dynamic experiences shared.

Making Meaning of Illness

Quest narratives. Researchers and practitioners have begun to pay more attention to the ways humans construct meanings from experiences, particularly illness experiences. Illnesses have broader socially and culturally constructed meanings and the ability to make meaning of illness experiences is constrained by preexisting and preferred scripts (Conrad & Baker, 2003; Frank, 2009; Frank, 2010; Kleinman 1988). The “storying” of participants’ experiences sheds light on broader meanings ascribed, and the internalization of these stories influences identity construction.

Each participant spoke at length about finding opportunity, meaning and purpose in their illness. Sometimes this meaning was hidden within larger narratives and at other moments it was the entire narrative. In Frank’s early work (1995; 1998) he describes three narrative frameworks available to hold illness stories; restitution, chaos and quest. “Restitution stories attempt to outdistance mortality by rendering illness transitory. Chaos stories are sucked into the undertow of illness...[and] quest stories meet suffering head on; they accept illness and seek to *use it*” (p. 115). Restitution stories fuel the modern medical model and everyday illness experiences, whereas quest stories make up most of the mainstream literature and personal memoirs/biographies about illness experiences. Restitution narratives were somewhat present in the stories of disruptions to daily life from exacerbated symptoms, infections and hospitalizations, but cannot contain the complexity of participants’ illness experiences. The lives of these young women remain continually interrupted, they have never lived in the absence of CF, thus it is not sufficient to narrate only the interruptions and focus on returning to health. Additionally, though these disruptions vary in intensity, they will never cease, and participants have an embodied understanding of the degenerative nature of their illness and looming expiration date. Speaking of the impact of illness disruptions Rachelle shared “sometimes you’re

like, I don't know how long I'm going to feel this good so I just need to go out and do things. I cannot stay in my house." Illness disruptions and hovering uncertainty help her to appreciate moments of wellness and health.

Marcie constructs quest narratives through her references to the 'perks' of CF:

I read it in a devotion... it was saying something about some woman who had been sick, but she used the sickness as like a podium to speak from right cause she could do that. So like the CF, which I think is a perk, is kind of like a podium and kind of like a stepping stone, saying like hey, I'm definitely not able to be doing this by myself... it is like... that's God behind me or with me and all that, and he's going to kind of cast that shadow.

Marcie uses her illness to draw closer to God and to share her faith and perspective with others. Framing her experiences as a "journey" she provides examples of her illness experiences shaping her or her relationships, favourably teaching and molding her into the person she is today. Illness then, although not necessarily a 'good thing', has meaning and purpose and keeps her life moving in a positive forward direction (Frank, 2009; 2010).

Rachelle also refers to her illness experience as a journey. As she constructs her identity she refers to lessons learned from her illness experiences, continually pointing to the positive impact of illness, making multiple comparative references to others, highlighting how 'lucky' she is. Talking about a particularly difficult hospital admission she says

That's probably the closest... to dying... I've ever been. So that, I think that definitely gave me like a... this sounds really cliché but like a 'don't sweat the small stuff' perspective. Cause I didn't really realize how close I was to dying until after it was.... I was healthy again. And I was like. Oh my God, like that was so close. So like after that a lot of small things didn't really bother me any more... like I mean I still spent some time like having pet peeves and stuff but... I feel like I am more big picture now than I ever used to be. And I guess that is definitely a CF kind of thing that made me like that. Cause I think a lot of CF patients are like that. They're very like... meh, the small stuff doesn't matter, because... at least you're not dead!

Drawing from the dominant cultural narratives available to her, she creates meaning from this terrifying experience, using it to connect with her 'self' in ways others, who have not had this experience, cannot. This challenge brings new strength, perspective and self-assurance.

Both Rachelle and Angella stated if given the chance they would not live their life over again without CF. Angella profoundly stated:

Would I do my life over again without it? [CF] I don't think I would, because I don't think I'd end up being the same person that I am right now. I don't know... if you asked me 'if you could get cured right now and have like, just be like 100% cured', the answer would be yes instantly but redo my life without it... I don't know. I don't think I would. I don't even know what kind of person I would be. Life would be completely different, so no I don't think I would.

She would not have chosen the illness, and would get rid of it tomorrow if given the chance to breath freely, but she likes the person it is shaping her to be. Angella frequently refers to her CF as being "intricately linked to her identity," so intimately connected to the inner fibers of her being that though it does not define her, she cannot be consciously separated. Storying her experience as a quest she embraces lessons brought by her illness, overcomes difficulties and allows herself to be transformed in the process. A perspective encouraged and promoted by mainstream discourse of health and illness (Frank, 2010).

Illness as a battle. Another prominent feature was the metaphor of illness as a battle. Here the energy shifted from gleaning positive lessons and attributes in quest narratives to an active *fighting* energy. The battling image appeared as vigilance against recurring symptoms, determination to live 'normally', and resisting constraining perceptions of others. This active energy spread to many areas of their lives, constructing a self perceived as a fighter, exerting personal power to 'prove' themselves; to themselves and others.

Angella's identity, for example, is as much constructed by who she is becoming as who she is not (Gergen, 2009). She spoke about actively fighting against confining implicit and explicit boundaries, striving to prove that she is, among other things, a competent and capable young woman. While Angella does not internalize these perceptions she is aware of them, finding them both humorous and frustrating as illustrated below:

Like at my summer job, it was [physically demanding] so people thought that like I wouldn't be able to do it because I have CF. Like they arrived and they thought there was some crippled girl coming to work with them. And then when I arrived they didn't know that I was supposedly the crippled girl. So like a few weeks in they were like, oh when is that crippled girl coming to work with us. And I was like, 'oh, ah, I think that's me, thanks.' ...[Laughs] ... So, I think a lot of people think that, that I am sicker and weaker than I actually am. The only way that I can really deal with it is showing that I can do things. Because me telling them doesn't mean anything, they're like 'oh, ok, like...'. They just don't like understand. And, and that's the only thing about Cystic Fibrosis, It's not a very popular disease, you know? Like you don't see it on TV very much....and when they do show it on TV, a lot of times it isn't very accurate. So, um... yeah... just people don't understand it, it's not like cancer which is a lot more popular in fiction and stuff and people are more aware of what it does and stuff... But like with CF, they're not aware of any of that. They don't get what it is, what it does, and they don't get how people, that there are varying levels of sickness. So, like all I can do is show them that I can do things... I already feel like I'm trying to prove myself so that I'm not like a stupid girl. Which is dumb, I mean like you shouldn't have to do that. But like, I already feel like I have to prove myself, so like when I have CF it's even worse. It's like, like I'm trying to prove that I'm not like just a weak girl, which is stupid, I shouldn't be but like I am. I get it. I can't help it.

The energy Angella exerts to prove herself reflects not only her immediate experience, but also cultural influences that privilege strength and resistance (Riessman, 2003). Another participant in a different context would not necessarily story her experience in this manner.

Living in a context and culture valuing strength she finds ways to embody and exude this strength, adapting and combining available cultural narratives (Frank, 1995). She acknowledges enduring suffering and pain, but examples of giving in to suffering and difficulties were absent, reflecting preferred cultural narratives about how to live with illness (Frank, 2000; Kleinman, 1988).

Marcie's accounts were also peppered with references to "doing battle," fighting and resisting. When discussing one of her final pictures Marcie described the importance of fighting to escape limitations and entrapments of illness and of 'the world'.

It kind of, [one of the photos] this one represents how I feel at times. So as you can see [the plants are] in an enclosed area... kind of like in life, it's kind of your world, right, see that like darker soil and stuff. but um... it's kind of like, you're kind of trapped in this world and everything. But like these plants, they're like seeing the light and they're like going for it kind of thing, and they want to escape of course. But then, the mesh, even though they can go through it, just kind of ignore that though, um, but there's always something kind of in their way and everything, until like the gardener... takes it off, kind of thing... or they can grow past it but I think that would be a bit worse.... [So] like, how I feel sometimes, is like, I feel sometimes trapped by the world, notice that it's also black mesh [around them]. So like, the world has like these traps, well they don't know that it's traps right? But they have like snares and stuff which can like hold you back, or if they grew up it would be kind of messy because it's then you know, then it goes around it and so then it's like, this dark mesh is kind of more entangled with it, and then it's really hard to get out. So... um... yeah just sometimes trapped in a world, and sometimes like I don't have friends who understand, [And CF is] like the black snares, one of the hindrances, just cause if I start thinking of it in the way of like oh, I have CF, then it's like... then I start losing like hope or something and going around it and getting ensnared by it... cause I'm going through this and all that. Then if you start thinking wrong, which I think would be like a tomato plant going the wrong way and getting more entwined right. Its... so CF can be one of the hinderers of it, cause if you start thinking of it... like oh CF's got

me... it's like, cause I guess one of the sayings is like I've got CF but CF doesn't have me or whatever. So yeah... sometimes it's like... I can be like 'oh, CF kind of has me', then it feels like, 'oh I can't do this anymore and everything'....

Marcie experiences an active battle against internal and external pressure, constructing a sense of self that is striving for freedom and strength. Expanding further, Marcie discussed a familiar experience of battling others' [mis]understanding of her illness and ability. Unlike Rachelle, Marcie's fight extends to consciously resisting internalizing these misconceptions.

It's just kind of like, you feel like, you start believing that they're thinking that you're like lazy. And it's like, then you have to fight yourself, like I'm not lazy, but I sort of am, but I'm not... then you have to remind yourself, like why can't you do it and stuff. Like it's a bit, you have your own little struggle in your mind, it's like, I'm not like how they say I am, but... and so... then you try to explain it to them, and then if they can't understand then it gets even more confusing. And so usually they end up just thinking you're lazy.

When asked about the impact of these perceptions Marcie paused, then stated:

Usually like, their opinions or beliefs about me that I'll start to believe. That's usually how I've always been, it's like kind of bouncing back right, so like, you think I'm this way boom that's what you get, you think I'm this way boom, that's what you get. It's like, kind of different masks for each person, and then when you're with yourself it's like whoa. Yeah, so... I guess they influence you by kind of doing more like how they would think it would be, and if they think this then I'll show them that, or if they think differently, then I'll show them that, but when I'm with myself it's usually more of a battle of being tired of just putting on all these masks, so it's just like learning how to unmask and just be that one person you know.

The silent suffering that accompanies chronic illness is pushed aside in these narratives as participants construct and present images of themselves as beating their illness, reflecting cultural images of 'successfully' living with illness (Frank, 1995; Kleinman 1988). Research demonstrates that beliefs about control and self-efficacy can be adaptive in chronic illness, perhaps these stories of battle reflect attempts to maintain or regain power and control,

overcoming disempowerment (Casier et al., 2008). The narratives were layered with more references to resistance and battle than included here, and remained a key feature in their identity construction. After all, as Marcie stated

It takes a lot, because we're like fighters, right, like with CF you're always have to be fighting, and just in the habit of fighting for everything and just trying to do things faster because like you never know when it's going to end right? So, you just kind of have to push your way through...

Embracing Multiple Layers

A person first. All participants struggled to express the multiple layers of their identity and the plethora of ways they believed CF shaped their identity. Their comfort integrating their illness into their sense of self seemed to correlate to the diverse socially constructed meanings associated with 'illness' at different moments in time (Kleinman, 1988). They expressed a similar sentiment to the young people interviewed in Willis et al.'s, (2001) qualitative study of young people with CF, stressing the importance of constructing their identity as a young woman first and then a woman with CF. In the words of Angella, "I am a CF patient but also a person, mutually exclusive". Though ever present, their narration of illness shifted from something that could be compartmentalized and segregated to specific aspects of their lives, to a factor intricate to shaping their unfolding identity. While illness was part of their developing identity, it was important for them to be seen as whole and healthy people, defying the narrow confines of a 'sick person' label, dynamic and ever changing, more similar to their peers than different.

Rachelle emphatically expressed a desire to be seen as a unique and dynamic individual, more than an illness as she shared instances when she felt invisible under a shroud of illness when others discovered she had CF.

I guess it's a little irritating, and I guess slightly dehumanizing. It feels like, until they get to know you, it feels like everything you say and do is over shadowed by the fact that

you're this person with an illness. So it's almost like the things that you say have less value or less weight because you're talking to them and you know all they're thinking is 'oh that poor girl, she has CF'. So it's, yeah, it's like the things you say don't matter as much. Until, like, in the end they do get to know you and they realize that you are a person, but just for the first little while, it's hard.

Beyond community members Rachelle felt even her health care team routinely failed to see her holistically and uniquely;

Like when you have CF they try to force you to do like lighter course load which is really frustrating sometimes, because you tell them, they're like just do 3 courses, but like I don't want to be doing my undergrad for like 8 years! So, like whenever you take 5 classes they're like, oh you're pushing yourself too hard, but then... it's difficult to not do that many classes and get your degree on time. So, my health care team, nurse, doctor, physiotherapist, everybody who takes care of me at the clinic... it's like they don't really realize that you also have like life and things that you have to take care of on top of your health stuff, so it's just gets frustrating sometimes. I mean, well it makes sense like they only see me in regards to CF, because that's like when, how they take care of me, whereas I have to deal first hand with all my real life shit... They tend to compartmentalize your disease from you. So sometimes they ask things that are just unrealistic. They'll be like. Oh, you're not gaining weight fast enough, you should be eating 17 cups of nuts a day, and like there is no way I could do that. Like I have to leave my house at some point! [Laughs] Sometimes I just have to tell them I can't realistically do that, and usually they are pretty understanding. But sometimes, like, you just have to say you're doing it and then not tell them you're not doing it, that's kind of just how I deal with things sometimes. Which is probably not the best way but...sometimes it's the easiest way to just get around doctors!

Perhaps due to power dynamics, or the desire to be seen favourably, Rachelle learned to hide behaviours and aspects of her life from her medical team and elements of her illness from peers. In attempts to be treated uniquely and holistically and fit the narrow framework of 'normal' Angella and Marcie also minimized or hid aspects of themselves they perceived as 'different'.

Interestingly, Angella had different experiences of compartmentalization, intentionally designating certain activities as 'sickness' related and others 'life'. When speaking about the photographic portion of the study Angella reflected that her photographs did not explicitly relate to her CF, "[this photo was from] just like one of those really nice days when we were like 'Oh yeah, I'm young, this is awesome!'" In later conversation about the photo she shared "I think it's the part of my life CF has nothing to do with!" Initially health and illness were perceived as binaries, mutually exclusive, reflecting mainstream restitution narratives focused on returning to health (Frank, 2010). When debriefing the entire research process however she elaborated:

Like, I didn't even think about CF when I was choosing [the pictures], like at all, I didn't even factor it in! So I guess that's sort of interesting, like why didn't I think about that? Cause like, that's what the entire study was about, but I like, that wasn't even a part of my decision making for this. I wasn't like, oh I should do this somehow to represent CF, I was like 'oh, I'll choose that picture'. Like just went through a lot of pictures and was like, that one works! None of them has anything to do with CF... But expect it did! [Because] I do think it is a big part of who I am... like I'll say, that [picture] doesn't have anything to do with CF, but then I think about it and I'm like oh this is about me moving away which is harder to do because I have CF, or like this is about my relationship with so and so which is like kind of tied in with my CF... so like that kind of thing, like it's so inextricably linked with my life that like I can't really think of it when I'm asking the question 'who am I?'... I guess it's really interesting how that, even though none of [the photos] really depicted anything about CF [initially], or how I thought they weren't related to CF, they all kind of are because it is an intrinsic part of my identity... perhaps that's a bit hard to capture in pictures. I mean I suppose I could have like my airway clearance device. I don't know... I think it's hard to capture that on film, cause I do think it's a big part of who I am. I really do. But it's hard to represent that in an image, like I don't really take pictures of myself when I'm in the hospital, because like, I'm in the hospital and I look like crap!

Whether due to her level of comfort with the photographic element of the study or narrow definitions of health and illness, the tension experienced by Angela is noteworthy. Additionally, it is interesting that none of the photos participants shared contained inherently medical equipment alluded to by Rachelle, yet CF was present. This powerfully illustrates the holistic impact of their illness.

Each of these young women appeared to struggle with multiple dimensions, contradictions and paradoxes of their developing sense of self, choosing what 'parts' to present to others. However, the relational processes they engage in when presenting themselves to others are constructive in and of themselves, forming knowledge of the self and identity. Perceiving the self as a fixed internal structure presented to others is limiting and perhaps contributes to the discomfort participants felt (Gergen, 2011). The dominant narrative of the self appears unable to embrace the many aspects of fluid identity, forcing some elements that cannot be represented within a cohesive whole to be left out or hidden, thereby limiting the identity possibilities available to participants.

Sick person. As they engage in relationships with the world and others, the participants appear to actively resist being identified as a 'sick person'. As young women who have CF, a chronic illness, they are *sometimes* sick and never fully 'healthy', but not one of them is a 'sick person'. The expectations individuals and social structures have of an ill person, and the expectations this individual has towards people and systems he/she engages with construct the image of a 'sick person' (Frank, 1995). One such expectation is time-limited periods of increased dependency and withdrawal from normative activities, creating some degree of helplessness and neediness (Frank, 2009). With a chronic illness such as CF, illness symptoms cause unpredictable disruptions, which impact all domains of a person's life for unknown periods of

time. As expressed by Angella, though the disease has always been there, sickness is a *sometimes* thing. Being viewed as ‘sick’ because of the CF did not fit for these women, requiring them to use more flexibility in defining sickness and in determining how ‘sickness’ informs their identity. Illness then can be conceived as not merely existing within each individual, but as something created and given meaning through social and relational practices (Conrad & Barker, 2010; Gergen, 2009)

Marcie expressed frustration and apprehension about being perceived as a ‘sick person’, and was fearful of the employment repercussions this reputation may perpetuate. Adding to this conflict, she also struggles with following the advice of her health care team about how to navigate this scenario. When talking about who and how she should tell about her CF, she said

I do care who knows, but I don't really care that much. Like if you're going to be employed though, then, as my doctors tell me, it's kind of like... keep it down low, cause then you have, like you know, the whole reputation of being a sick person... it's weird... so the reason I wouldn't is just mainly because the doctor said it's not a good idea...

Marcie understood this advice and shared the resistance to being treated differently, but struggled saying “It’s odd, because it’s in my nature to be like... okay I’ve got this, all right, got questions, research it! But, I kind of respect [the doctors], [they’re] kind of older than me, and probably know a bit more than me so I guess [they’re] right...”. Tentative trust in her doctors expands the meaning of her illness. Following the teams’ advice over her opinions brings the illness out of the realm of her bounded body, into the social context and relational processes in which it is embedded (Conrad & Barker, 2010; Gergen, 2011).

Much has been written about the shame and stigma associated with the unpredictability of illness (Conrad & Baker, 2010; Frank, 1995; Kleinman, 1988). Each participant regularly fought against potential stigma associated with illness and symptoms. Most prevalent was the

unpredictable, rattling cough that limited employment opportunities and led others to assume they were smokers. A secondary stigmatizing factor was the reaction of others who had minimal understanding of Cystic Fibrosis and limiting definitions of ‘being sick’. Illness experiences are culturally shaped, there are anticipated ‘normal ways’ of being sick and creating meaning for illness symptoms (Conrad & Barker, 2010; Frank, 1995; Gergen, 2009; Kleinman, 1988).

Participants repeatedly stressed that the shared term ‘being sick’ was a misnomer as it means something different to them than to peers living in the absence illness.

As Rachelle eloquently expressed:

Probably the most difficult, because like when you say, like ‘I have CF’, then it’s like, [I have to explain] ‘but I’m not hooked up to oxygen or anything’, and I do look really normal. So like, trying to explain to people sometimes like, I just, I and really not feeling good that day because my lungs are filled with fluid and I can’t breath very well. Just trying to explain stuff like that, that you just have days when you feel awful and there’s no one thing, to explain what makes you feel awful, it’s a combination of things. Because like, you also have um, digestive problems when you have CF so sometimes I just feel nauseous some days and stuff. And trying to explain that to people is just really hard. Because like, usually you have a symptom you can isolate and it’s like oh it’s this thing. But just saying you just feel overall shitty that day it’s hard to get across. Because like a lot of people feel shitty and it’s like dude it’s manageable. But when you feel shitty sometimes and you have CF, it’s just not. Especially when you’re working it’s like, jobs are the hardest. Because like explaining it to your boss is so hard. Just being like I can’t come in today because I can’t breathe, like it’s so hard. And like if you try to explain it, like I’ve tried to explain to a lot of employers that I have CF and they’re like, oh is that like asthma? Like, they just don’t understand.

The current cultural climate perceives ‘being sick’ as a symptom that can be isolated and treated, a puzzle to be fixed so one can return to the goal of optimal health (Frank, 1995). CF is multi symptomatic affecting multiple organs, literally leaving a person breathless, return to

‘health’ is relative. Symptoms can be alleviated but with no cure, CF can never be “fixed”. It lies outside modernist expectations of illness. The participants reside in the mystery of recurrent illness not the certainty of restored health. Their understanding of health, illness and identity ebbs and flows, requiring flexibility and movement. The collective understanding of CF sickness within CF communities creates strong bonds of support and connection but this is difficult to translate to the dominant culture when the understanding of sickness differs dramatically.

The participants all stated they wished there was a more ‘mainstream’ understanding of CF, and flexible definitions of sickness and ability. Interestingly, they stressed that a more common understanding and shared language would not change how they saw themselves. Rather, if CF was more ‘popular’ within the dominant discourse it would change how they presented themselves to others, particularly giving them more confidence to share illness experiences as they would not be as quickly categorized as different. They alluded that they would be more free to share ‘all’ of themselves, and be accepted and seen holistically.

I just think maybe the way I would bring it up in conversations, like the way I would bring it up to my employers and friends, that might change a little bit. Because like if they did know more about it, it might be less.... it would be easier to like ease them into it I guess. Cause it can be like... like I said it can freak people out... enough that they like have a complete conniption fit like my boss did, but you know. Stuff like that might not happen if people knew more about it... yah... it wouldn't, I don't think it would change my self perception but it would change other people's perception of me (Angella).

Relational beings. When speaking about layers of identity each participant noted the importance of relationships, alluding to a reciprocal, co-constructed identity (Gergen, 2009). While they talked about being individual beings; separate and whole, they also recognized they are continually constructed through contextualized experiences and relationships. As Marcie states:

Who I am is the family... Usually like, their opinions or beliefs about me, I'll start to believe. That's usually how I've always been, it's like kind of bouncing back right, so

like, you think I'm this way boom that's what you get, you think I'm this way boom, that's what you get. It's like, kind of different masks for each person, and then when you're with yourself it's like whoa. Yeah, so... I guess they influence you by kind of doing more like how they would think it would be, and if they think this then I'll show them that, or if they think differently, then I'll show them that, but when I'm with myself it's usually more of a battle of being tired of just putting on all these masks, so it's just like learning how to unmask and just be that one person you know.

Through interactions with others Marcie's identity unfolds. Rachelle also alluded to the relational processes her identity construction, referring to the impact of important childhood relationships. She repeatedly referenced important people in her life as being intricately tied to her identity construction, both family she was born into and friends who she consciously chooses. Throughout our conversations she referred to her parents or long-term girl friends as shaping her values, perceptions, priorities and personality. She compares herself to her peers and sees them as inspiration to be a 'better' person. Unlike Marcie however, Rachelle does not internalize other people's perceptions, but actively rejects or embraces perceptions as she sees fit, expressing her agency in constructing her identity stating:

I guess I define myself a lot by who I'm friends with like I'm really careful with who I make friends with and I'm really proud of the people who I am friends with...I honestly don't know what kind of person I would be without these connections to other people. It's hard to think about myself as an isolated person.

Gergen (2009) views the self as continually in motion, co-constructed by relational processes, simultaneously constricted and set free by the possibilities presented within each relationship. Perhaps this lens provides a new way to look at the flexible and dynamic identities these young women are constructing. If the assumption was not of a core or unified self but of a relational self in motion, continually developing through time and relational processes perhaps the participants would experience greater freedom and possibility in their identity construction

rather than experiences of exhaustion, or adjustment difficulties reflected in literature. Perhaps then there would be room for a slippery, flexible, culturally constructed, paradoxical identity.

Rachelle and Angella were in the unique position of having a close family member who also had CF. They both highlighted the importance of this relationship in constructing a sense of self that fits in and has experiences of sameness and difference, and does not rely as heavily on external acceptance. As Gergen (2009) stresses we are all constrained in our actions by the meanings others make of our actions, "one acts, another responds, and in the interchange meaning is born" (p. 41). Rachelle and Angella's illness experiences were regularly responded to as normal; the meaning of the illness was constructed as typical and expected rather than different or surprising. Rachelle felt this relationship helped her resist disempowering and limiting narratives to exercise more flexibility in how she sees herself. In Rachelle's words:

I guess that's what it does say, is that it's a lot easier to deal with something like this, when you have someone that you don't have to explain it to, they just know. They're there right, so they just completely, like you don't have to say... I'm just... I have to go to bed early because I'm so exhausted from not being able to breathe today. They just know, they're like yeah whatever, see you tomorrow. You never have to explain what this strange medical instrument that you're using is, they just know because they're doing the same thing. And it does make it a lot easier to deal with other people who might not understand it because you do have a person who does.

Difference. Another key component was participants' sense of being both similar and *different* from their peers. These stories came quickly and flowed fluidly; being different was a familiar feeling, both embraced and resisted. The participants continually compared themselves to others, and their tales were laden with unspoken assumptions about what constitutes 'normal'. This feeling of difference was not static but was constantly evolving, fading from background to foreground depending on their social climate and culture. It is incomplete, however, to merely

say that participants experienced themselves as different from their peers. 'Feeling different', striving to minimize difference, by creating a sense of normalcy and accentuating similarities to peers living without illnesses, is reflected within literature exploring the experiences of young people with CF and other chronic illnesses (Christian & Auria, 1997; Tyrell, 2001; Williams, et al, 2009). More beneficial and congruent with narrative research is to explore the meaning attached to this sense of difference, and its influence on their unfolding identity construction (Gergen, 2009; Riessman, 2001).

The participants experienced both an internalized sense of *being* different, and a keen awareness of *doing* differently, particularly regarding activities of daily living. Angella described her CF as 'hidden in plain sight', Rachelle stated it is largely invisible; a "private experience with outward symptoms that unfortunately people are curious about". Until they are hit with rattling coughs or take medications publicly, their illness is not evident and they can 'pass' as the same as peers living in the absence of illness. This is superficial however, because they still ultimately feel different from the socially constructed 'norm'.

The sources for this perceived sense of difference were often CF related, but also connected to family values or upbringing, and always determined through social comparison with an 'other'. Referring to the known sense of difference Rachelle said:

I grew up in a small town, but I really never fit in there because my parents are really, really left wing, kind of like socialist, radical sort of people, so I was raised that way. And it was really hard to reconcile that with like the very right wing kind of small town that I grew up in.

This family narrative provided particular identity options for Rachelle, 'not fitting in', and being part of a family who does not want to fit in, is embraced as another element of her unfolding, dynamic identity. She seems to embrace the 'differences' from reasons other than her

illness more easily “I like being um, the centre of attention for things that don’t relate to my health at all. So when I am sick and stuff I usually try to down play that a lot and not really talk about it, but I like to play up things that don’t have anything to do with my health.” She has a strong sense of how she wants to be seen, emphasizing her strength, dramatic flare and vitality privileged in society rather than illness, suggesting some difference is more ‘acceptable’ than others.

When talking about her experiences of difference Angella stated:

Well, because of having it [CF] you already feel different from other kids. So you don’t, at least for me... I was like, well I’m already different anyways, so trying to fit in wasn’t as big on my list because I was like I won’t really anyways.

While peer acceptance was important, she thought attaining it was less crucial for her than it was for her peers saying:

I kind of just like had identified, I was like I was ok I’m not like... the pretty one, I’m not the sporty one or the jaded one or whatever... so I was like I... am... the... So I guess, basically, I saw myself as like this sort of jaded obscenic in high school, which so many people do. Like oh yeah, I’m like the one who’s different from all the others, all the other teenagers.

Not only are the options available limiting, but the language used to describe the identifying options in the dominant narrative is constraining, static and fixed (Gergen, 2009).

Marcie on the other hand has vivid memories of resisting her sense of difference, felt because of CF and familial reasons, prioritizing fitting in and belonging, frequently hiding outward differences often at a cost to her own physical well being.

I usually suppress my cough, because I don’t like coughing in class...the teacher is talking so sometimes they’d be like you can go out in the hallway or something to cough but then in my mind it goes back to the time when I was little having to go out of the room to take my enzymes, and I’m like ‘uh oh’, I don’t want to have that [extra attention] ... so

I'd be like [suppressed cough] all good. Doing that wasn't the smartest though.... Like I did that during exams cause it's like a huge gym, and it echoes pretty much. And so I never really coughed and I was pretty much holding my breath! And, one time after that I literally couldn't hardly breathe, like I got up the stairs and luckily that's where [help] was and I was like I can barely breathe! Cause I'd been suppressing it too much, and so from then on I'd be like 'that's a stupid idea'.

Expanding on "feeling different" Angella shared another quest narrative, articulating that CF has dramatically and positively impacted her world-view and approach to life;

I just often see things a little bit differently than most people do. And I don't want to be like I'm so much more special than anyone else I just, this is what I've noticed in my experiences over the years. Like I have a different like, life experience than a lot of people or what, but like that's something I notice...I think CF definitely plays a big part of it. Because, there's the whole, like for example, you're different from everybody you know. You have... as sense of mortality before everybody else, you go into puberty later, which honestly I think, like, at the time, I think it was a good thing. Because I knew lots of girls who...were...like, they developed really early and they got into, they had lots of relationships and stuff like really young. It sounds really terrible but I think it really...it gave them bad expectations of what they thought relationships could be, so they've had like strings of terrible relationships, with awful people. And, like I never did that, it's like I developed a sense of self before I started dating, and so I think that really helped me out, and I think a lot of that was because of CF. Because I wasn't, like I looked like a 12 year old so it was like, I didn't date... I think it also influenced my political views, too, a lot actually. Because when you're, when you have an illness and you have a disadvantage, you kind of start like, I don't know I just saw the world in a little bit of a different way. Ok, like maybe, free health care is a good thing! It helps that I grew up in Canada where we have public health care too, it also helps that my parents are like raging socialists, so there's probably that too. But like, definitely an integral part of my self-identity.

I asked participants when they realized they had a diagnosis of CF. Each of the young women believed they always 'knew' they had it, but the label of CF was meaningful when

differences from their peers became apparent, (school age), and were linked back to an illness called CF their peers did not have.

I knew I had CF from when I was little, because I had to start doing physio when I was really young, so my parents were doing physio on me when I was like 3 years old kind of thing. But it didn't really register that there was actually something different about me until I started school. I knew that no one else had to do these things but it just kind of hit home a lot more when I was around my peers and they didn't have to worry about any of the stuff that I did. And it just made me realize... like how... how... alien my life was compared to theirs I guess (Rachelle).

This experience is similar to the adolescents in Christian and Auria's (1997) qualitative study, where symptoms and medical regimes were not perceived as abnormal, or due to 'illness' until young people spent more time with their peers, and learned that their daily routine and stamina differed from the 'norm'. This highlights the socially constructed nature of illnesses, where illness and difference categories stem from agreed upon 'expert' expectations of 'normal' and "ideas about what [is or] is not acceptable or desirable" (Conrad and Barker, 2010, p. 68). Perhaps more difficult than the illness itself is the experience of being 'othered' by structures and people who perpetuate socially constructed notions of 'normal'.

Each of the participants knew their normal was very different from their peers' 'normal';

It's weird because you kind of expect yourself to, you know, usually die younger, especially because like when I was born you know I don't even know what the age was, 15? Probably lower. But... so, you always expect yourself to die before other people you know, especially your parents. You expect you to die before them, like even when my dad died it was like what? It was kind of weird cause you're not expecting it, but then it's like I just experienced something that normal people will experience. But it's just you know I had prepared myself the opposite way so it was kind of like odd (Marcie).

A painful experience for anyone, but she felt this experience was different, and perhaps she was less equipped to deal with it given her different expectations of 'normal'. Later she

shared connecting with the broader CF community brought solidarity and helped bridge the gap between her normal and others.

Being Flexible

Future planning. Similar to the experiences of individuals with CF reflected in the literature, future planning weighed heavily on participants' minds (Hains et al., 2009; Jessup and Parkinson's, 2010; Johannesson, Carlson, Brucefors & Hjelte, 1998). When speaking of future planning they acknowledged the anticipated end of life age may be extended, but a 'best before date' hovered. Many areas of future planning were discussed, but congruent with literature exploring identity formation, career aspirations, dating and/or marriage, and end of life appeared most relevant to their identity constructions (Côté & Levine, 2002; Kruger 2007). The disruption of unpredictable symptoms and shifting goal posts of life expectancy seemed to perpetuate the largest amount of dis-ease in navigating "identity forming" tasks. Participants seem to embrace both the dominant cultural narrative giving importance to these normative tasks but also adapt a fluid, flexible sense of self as they engage in these life events uniquely.

Reflecting cultural values placed on employment, the participants want to 'do something' with their lives, and engage in meaningful work that they enjoy and would make them happy. The young women believe that their CF will likely interfere with career options and that although working frequently exacerbates symptoms, the benefits outweigh the costs. As vocation and identity are strongly interconnected in Western society, the tension expressed within our conversations is particularly meaningful. Marcie, in a season where her CF symptoms felt quite intrusive, spoke at length about the burden of looking for work while dealing with a roller coaster of unpredictable symptoms, and external pressures.

It's kind of weird right now, not having a job, 'cause right now there's so much stress, cause like [my family's] pushing me for a job. So like, everyone wants me to have a job

and get money, and like I don't object to that, but I don't think I can commit to that. So it's really kind of hard. Like I have these dreams and trying to put them together so I can still do something with my life I guess...I'm almost frightened to get a job cause it's like with the symptoms it's like, I don't know if I'll go to the hospital. I don't want to go to the hospital, and with that I don't want to have to get a job, I want to focus on getting healthy. Like sometimes with that, then your emotions get like, cause you're tired and then fatigued so your emotions are going a bit haywire and everything, so then it puts a strain on relationships and stuff, right. So then it's like, then you have to re-fix that, so then with it, with the symptoms, it's hard to do pretty much a lot of stuff.

Living in a culture and time where one's identity is intricately linked to occupation, and career aspirations, and one's worth is tied to being a 'contributing' member of society, present and future employment limitations present unique challenges to her unfolding sense of self. Marcie creatively dreamed of meaningful career aspirations, but struggled to meet broader societal expectations and not internalize negative images. Rejecting these limitations required flexibility and fluidity in her sense of self; paradoxically limited and able, adjusting her dreams to fit her ever-changing reality.

Rachelle's relationship with work differed. She has a strong sense that she will not live past 40, so planning for a 'typical' life of working until retirement does not fit for her. She rejects dominant time lines, striving to embrace a more flexible vision of herself and future.

I still can't imagine myself living past like the age 40. Like I can't imagine. I don't think about dying all the time, like I don't, but I can't imagine my life past the age of 40 I never think, like, I just think, I'm not going to live that long. And it's it, it definitely makes me like, probably not plan for things as well as I should because like, I don't take it seriously almost, like it's like, what does it matter? It's not like I'm nihilistic or anything or even that I'm sad about things, I just deeply feel that I'm not going to make it that long, so like, long term plans seem a little bit redundant to me... Whenever I think about what I'm going to do like after I get my diploma and like working full time and stuff. I always think like 'yeah that might happen, but like I'll probably die a short ways into it.... So like the

idea of just working my whole life and then retiring, I just can't picture it. And I think it's just because like, I think that I'll be dead...

She is however, going through the typical motions to achieve career aspirations by attending post secondary school with a specific career goal in mind but seems uncertain about how to do this while keeping her timelines in mind. Havermans, Colpaert, Vanharen and Dupont (2009) explored the relationship between employment and quality of life among people with CF. This study suggested that those employed had an increased sense of control over their illness, a deeper sense of being valued and appreciated, and higher 'health related quality of life' scores despite the fact that working placed them at a greater risk of health deterioration. While not being able to work as desired impacts quality of life, it is important to acknowledge that it is not only the act of working itself, but the socially constructed value attached to working that brings meaning (Gergen, 2009).

Typical for young women their age, participants spoke about the joys and difficulties of dating and finding a compatible partner. They discussed current difficulties in relationships and earlier challenges; particularly the impact of delayed puberty which will be discussed in the gender section. While they each identified as self assured, confident, dynamic females, undefined by their illness; CF reared its head in the intimate area of relationships, raising difficult questions of vulnerability, intimacy and security. Rachelle spoke of not wanting to 'saddle' a partner with a 'sick person', alluding to the question of what makes a female a valuable or pleasing romantic partner, and whether or not she fits this mould.

And also definitely the whole mortality thing, um, has made me wary about long-term relationships and stuff. Because I feel bad about, I guess, like saddling someone with someone who is not healthy and who could die. So. I definitely keep people, well romantic partners, at a distance. [I date, but] I have a lot of trouble seeing myself, um, seeing, as being permanently with somebody I guess. I never see myself as being one half of like a

relationships unit. Even when I'm dating someone I never see myself in that way. When you are in a relationship with someone, there's a different level of trust and dependence than you have with your friends. So like, when you're dating somebody and if it's long term, you are committing to that person and I always think about the fact that they're committing to someone who is... sick. And who is probably going to get worse, and like, the fact that they're going to have to deal with that, and I don't trust a lot of people to be able to deal with that I guess. So, I don't know, like I think that would really be awful and then they can't handle the fact that you're sick and they leave you or something? That's just awful!

Marcie and Angella also articulated similar fears about how a future partner would cope with inevitable illness disruptions, and potential early death; fearing both the partner's ability to be a supportive and their ability to handle it themselves. These fears are echoed by women in Johannesson et al.'s, (1998) study as well, and neither the women in that study, or my participants had guidance or support to navigate these challenges.

The timeline of CF added additional pressure to 'find someone' soon. While many young women feel their 'biological clock' counting down, the clock for the participants ticks as a loud reminder of shortened life expectancy and consistent health.

It also can be like scary because if you're planning then it's like, huh... because for a relationship or anything, it's like I've always, like just in case, I've always said like, 25 get married kind of about then. If not or if I don't have a potential kind of thing, then its like no [marriage], because I don't want to die on my husband or on the kids, especially because like the kids will probably not be very old if I got married after that. So it's like ah! But I have to be a bit more lenient because [discussing life situation of young man she currently likes] that's maybe about like 8 years [until he could get married], and then like I'll be past 25 by then so it's kind of like you have to let that go. Even though that was like my set, like 25 or no person! It's kind of weird cause then when you see the stats, but like if they're going up I could switch my age a bit more but it gets nerve wracking, cause it's like you don't want to die on them right? (Marcie).

Although not spoken about as fervently, this also influenced their desire to have children or not. Two stated definitively they did not want children, questioning the ethics of having children when you have shortened life, and the toll it would take on their own bodies. It would be interesting to explicitly explore how not having children influences self perceptions as attractive mates and women, as the dominant cultural discourse still privileges women's role as procreating mothers and wives, a mold they do not fit. Again, the narrative shaping the dominant discourse informs their experiences, but appears limiting for these young women, calling for immense flexibility in their self perception and plans.

Gender. Gender featured prominently within the narratives, both explicitly stated, and implicitly hovering beneath larger narratives and themes. All three women struggled with contrasting and paradoxical images of femininity, gender and attractiveness and embraced dynamic and fluid ideas of what it means to be a woman, and a woman with a chronic illness. They each identified as cisgendered, and had multiple experiences challenging, rejecting and embracing socially prescribed gender roles. The dominant understanding of what it 'means' to be female shapes how young women understand and construct their identities as females (Gergen, 2009). Both Rachelle and Angella spoke extensively about the impact of delayed puberty; particularly feeling 'invisible' to boys until they were approximately 17 years old, and started to 'look' like teenagers.

I was under the radar of dudes until I was like 17. I guess this has made me like, just a little bit cynical in general, because as soon as I did hit puberty it was like suddenly I was a person. Because before, I did hit puberty, it wasn't that I was friends with guys but they just weren't attracted to me, they like didn't acknowledge my existence, they didn't talk to me. And then as soon as I did hit puberty and then did look like a teenager, suddenly there was like all these guys who actually wanted to be my friend, and I was like are you fucking kidding me? And I was like, well you know what, it's not that important for me to

please these people, and so I've kind of had that attitude ever since... which might not be the best thing because it is a little bit combative and I've probably judged guys too harshly before I know them... so that would be the down side of that... (Rachelle).

Similarly, Angella stated;

CF is hard when you're going through puberty because you um, well actually you get delayed puberty, which sucks! So like I looked like a 12 year old until I was like 16... That really, that was really hard, that was probably one of the worst things of having CF as a teenager cause it was like, I really, I just really didn't like my body. And it wasn't like I thought that my body should look like something else, I just was like... I should look like an adult now and I don't! I should look like a teenager and I don't. So that really bothered me, because up until like grade 10 I hadn't gone into puberty, like I was probably one of the other girls that was like 'thank God I finally get my period!' And now, I'm like, 'what was I thinking'?

Being female meant maturing by a certain age and receiving attention from members of the opposite sex, having this experience later further marked these women as 'other', calling for flexibility in determining for themselves what it means to be female. Marcie also spoke of delayed intimate relationships with men, and feeling 'behind' her peers, but she was not certain how delayed her puberty was and linked it to her sense of self more hesitantly.

Delayed puberty is acknowledged in the literature but few studies explore how young women make sense of this experience and adapt. Johannesson et al.'s (1998) qualitative study is one of few studies exploring the psychosocial impact of delayed puberty and compromised fertility among young women with CF. Among other things, Johannesson et al.'s study highlighted that adolescents worried immensely over delayed puberty and appeared to avoid close relationships with members of the opposite sex. Rather than avoid relationships with men, or deny their own sexuality (as claimed in the literature) the women in my study told stories of being rendered invisible; reflecting a different locus of control. Rather than being perceived as

deviant, isolative behaviour, the lack of relationships with men was a response to gendered notions of attractive/unattractive and cultural rules of engagement with the opposite sex.

In addition to feeling frustrated and invisible to men, both Rachele and Angella felt the delayed puberty led them to develop a 'stronger sense of self'; another demonstration of quest narratives as they construct positive meaning (Frank, 2010). For me this opens up curiosity about discourses still tying women's identity to a relationship with a man. Perhaps this is one aspect of what these young women were resisting and why they see their experience positively.

Historically Erikson (Côté & Levine, 2002) wrote that women developed their identity later than men, after they had achieved their marital or relationship status as their identity is tied to their partner. While these ideas are widely accepted as outdated, inaccurate and sexist, similar ideas remain embedded in dominant discourse surrounding relationships; pressuring young people to be in romantic relationships to be 'fulfilled'. Rachele articulates another quest narrative, and distinguishes herself from peers who engaged in earlier relationships alluding that many women continue to define themselves by relationship statuses or images of femininity or beauty.

I'm pretty independent and self-reliant. I have a really good self-esteem, like, a lot of the issues that I find a lot of young women and girls are plagued with, like self-esteem issues and what they look like and all, that's never really been an issue for me. I kind of think part of it, it's actually hilarious, because like it all comes back to CF in a lot of ways. Because when you have CF you physically develop later, like you don't hit puberty until you're like 16 or 17, so I wasn't really objectified by guys until I was like 17 so I found it way easier to deal with it when it did happen and I was like oh yeah, okay, I got this. I wasn't like 12 and really confused about what was going on. I had a really well developed sense of self before I had to deal with any of that... and I think [this helped me to] realize that there are a lot more lasting and important things about your identity other than the fact that people think you're hot. Because I, I had to, cultivate a personality, because um, I was invisible in a lot of ways before I kind of hit puberty... so I

was a fully actualized person I guess, before I became physically attractive and that really influenced how I do things with my life. And I think as a result I never went through that phase where, I really felt like I had to be really attractive to please somebody. So, as a result, like I never, had a problem, like making myself really ugly to do something funny, or to do something that I really wanted to do, or like sacrifice my femininity kind of thing.

Willis et al.'s (2003) qualitative study exploring the role of gender suggests young people with CF may be more likely to endorse traditional notions of masculinity and femininity than their peers who do not have CF. The women in my study appeared to endorse a dynamic and fluid idea of masculinity and femininity, with both traditional and contemporary influences. They emphatically resisted being seen as a weak 'girl', insinuating that being perceived as a weak *girl* is somehow worse than just weak. The current social climate requires women to be strong and independent, who can (and should) be and do any/everything. The women in this study embraced this image of strong femininity, but struggled to concurrently hold the reality of limitations of their illness. They constructed fluid, paradoxical self-images of women who are strong and weak, healthy and sick, independent and dependent. They appear to vacillate between with mixed emotions of humour, reconciliation and determination depending on how they were received.

Becoming an adult. Literature exploring identity formation references the importance placed by Euro Western culture on adolescents to 'differentiate self' from caregivers and achieve 'independence' (Côté & Levine, 2002; Kroger, 2004). Much of the literature about young people with chronic illnesses acknowledges that achieving this independence is particularly difficult for these young people but it does not explore how individuals make meaning of this or its impact on identity. Themes of dependent-independence in the quest to become an 'adult' were pervasive throughout participants' accounts, questioning whether achieving the independence taken for

granted by those living in the absence of illness was possible or desirable, or if the type of independence they enjoyed was sufficient.

Independence appeared to be a slippery topic; on one hand glorified in mainstream culture and held as a powerful symbol of adulthood, on the other, an elusive concept, inaccurate and unattainable. Each of the women identified as being very dependent on their family and friends, in ways that differ significantly from their peers. However, they also presented and saw themselves as freethinking, independent women in the world. There was a tension between these two images. It seemed difficult to be both independent in the current, dominant understanding of the concept, while also requiring physical, emotional, and medical support from others. There appeared to be a battle between the two, one fading to the background as the other became dominant; one is either dependent or independent. Constrained by the possibilities available to them, they struggled to construct an identity where both coexist with equal strength.

Marcie has an internalized idea of what being an adult "should" look like, and struggles to fit her needs into this definition. "Sometimes I want, just a little help. I know it sounds, like you know, you have to be an adult, it's all good, but it's like just once or twice it's need a phew, break you know? Cause it's like hard right to always fight your own battles right?" It is ironic that during the time period that the dominant narrative encourages independence, her illness worsens, increasing her dependence on family and friends.

Rachelle appears to struggle with how her increased dependence is viewed by others, suggesting it is a potential source of shame and stigma that she resists.

I've always been aware and bothered by how much I have to depend on others because of my illness. So... staying as independent as possible in the areas that I have control over has always been really important to me. Sometimes like the increased dependency that I do have on my parents is kind of frustrating for me. Not that they ever complain about it,

or like I'm embarrassed about it. It's just that I wish I didn't have to rely on them for some stuff. I think I'm more emotionally dependent too. Just because we have a really good relationship and they do understand the whole CF thing. So, I feel like sometimes, like if I'm really having a trouble dealing with the disease and like they are people who I can talk to. And so, I do feel pretty dependent that way and sometimes like, I wish I wasn't. I just don't like relying on other people that much I guess, in general. Because like you never know when those people will randomly disappear from your life... Like I just wish I could deal with that better. But I guess everyone has people they depend on right. Like, that's how you live your life. And how you get through, you have to have connections with other people.

Despite her conflicted feelings about dependency, her narratives are full of celebratory stories of achieving independence, moving towards an ever-shifting target of 'adulthood'. Speaking about dependence and independence begs the question; at what age does a person become an adult; what milestone must be reached to *arrive* at this stage? Major Euro Western assumptions underlie ideologies of adulthood; presenting it as something to *reach*, *master* or *attain*. As social constructionist thinkers highlight, such technical, rational and pragmatic perspectives of knowledge and becoming ignore collective and contextual processes, (Gergen, 2009; White, 2007) limiting identity options available. The women require greater flexibility and dynamism in their definitions of adult independence as they negotiate the unfamiliar terrain.

Relationship to body. The embodiment of illness is a pertinent component of this inquiry, as “people certainly talk about their bodies in illness stories; [but] what is harder to hear in the story is the body creating the person” (Frank, 1995, p. 27). The literature exploring body perceptions and connections among young people with chronic illness typically focuses on body image, self-esteem or body mass index. Such discussions appear quite narrow, as they do not explore the meaning created about living in a body that is unpredictable, limiting and different from the norm, and its impact to identity construction.

When I began this inquiry I initially hoped to use the body typology frameworks suggested by Frank (1995) as an analytic tool to understand participants' body-self connection. Through my analysis however, I realized utilizing these specific body typologies may minimize the depth and complexity of shared experiences and may contradict the spirit of dialogical narrative analysis. As Frank (2010) aptly states while valuable reference points, “typologies risk putting stories in boxes, thus allowing and even encouraging the monological stance that the boxes are more real than the stories, and the types are all that need to be known about the stories. In a world where simplification is a pretext for knowing, and knowing is a pretext for controlling, typologies are risky” (p. 119). Thus I again turned to Frank’s (2010) later work, which while still acknowledging that stories are shaped by the narrative resources available, has evolved to stress the value of hermeneutical listening with stories as they unfold, rather than viewing them through a preconceived framework. While elements of participants' relationship to their bodies have been alluded to, this section explicitly discusses key elements shared about their body-self connection.

When asked about their relationship to their body each participant immediately assessed their physical attractiveness, and expressed conflicting levels of acceptance, frustration and disappointment with their body's appearance, performance and predictability. Interestingly, they continually compared themselves to culturally constructed gendered beauty norms and expectations, unattainable for every woman, not just those living with illness. Metaphors of fighting, resistance and entrapment were present, as they struggled to express the multiple dimensions of their body-self connection.

Marcie's powerful metaphors of fighting were rampant here, highlighting internal battles:

So, yeah I'll do like my enzymes and the treatments but like the lung clearance [to take care of my body] [but] I'm not very good at that so I guess in that sense I'm a bit against

the body. That's my fight with the body, I should do it but I don't want to do it. So its kind of you know what to do but you don't want to do it just cause you're so sick of the stupid body! It's like no, you're not going to get your way, not this time! That's a kind of stupid way to think right, but in the end that's not a good route to go, but it's like, yeah. So hmm, so I guess I have a pretty good relationship with my body. [But] sometimes I don't always know what's going on...[It can be] very frustrating... like when I was younger. I just would cry because I just was tired, tired of CF, tired of the pain, tired of all these stupid treatments, you get tired of it right? Tired of the body, it's like I want a new body, just to be healthy just for like one day. Just to breathe normal for one day or even a minute. So it does get extremely frustrating, so it's like, just sometimes you get so tired with your body, so like when I want to be taken care of, it's like I don't want to fight with my body anymore, I just want someone else to just take care of my body...

When talking about the body, the physical manifestation of illness symptoms, Marcie gives voice to her suffering (Frank, 2010). She is not concerned with the social responses to her symptoms, yet socially constructed frameworks of 'normal' 'healthy' bodies inform the meaning she constructs (Frank, 2009; Gergen, 2009). Following directions of her medical team for her treatment regime seems to perpetuate a dichotomy between mind and body, perpetuating disempowerment, relying on others to decipher and decode her body rather than 'knowing what was happening' herself (Kleinman, 1988). In illness she refers to her body as separate entity, stating 'the body' vs. *my* body or me, disembodied the battle shifts; pitting mind against body (Wilde, 2003).

Rachelle has a strong awareness of her own limitations; not merely socially constructed by societal norms and values, but those tied to her stamina. She often feels 'trapped' and continually fights against this, constructing a flexible identity and dynamic way of engaging with her goals and dreams as she realizes how intimately her CF affects her entire life.

Physically, okay the way I look and stuff, I have a good relationship with my body. Like I like the way I look and stuff, and feel good about myself. I guess on a shallow level I do

have a good relationship with my body. Where it starts to be a problem is sometimes I feel like I'm trapped in my body. Like I feel like it's this limiting factor. Where, I have things I want to do and I can't do them because my body is inherently flawed. So I guess it's like, I like my body, and I'm comfortable with it, and like, it's a good body to have, I'm glad I'm not paralyzed or really morbidly obese, but at the same time, I do wish I could make myself like more healthy, so, it does feel a bit limiting sometimes but generally I do have a good relationship with my body...I feel like I have a stronger like tie to my physicality or something than my peers [without CF] do, which sounds really weird. But I guess like, the way my body is physically really effects how I'm able to live my life, like if I'm having a bad day, sometimes I can't go to work, or I can't go to school. Or I can't, like, sometimes like when your lungs are full of fluid and you're having trouble breathing, like you're so tired. You can't stay, like sometimes you'll sleep for 12 hours, and that's usually when you're really sick, but it does really affect how you do your day-to-day life. So I guess I am really in tune with when my body is sick because it limits the rest of my life so much. So I guess, there is way less of a body-mind disconnect for me I think. Yeah, I think that's a good way to put it... [and before I lived on my own] I never thought of it [CF] as a big of an inconvenience as it actually was I guess... I just wasn't aware before 'cause I just had so much support and so many people helping me with everything. [I think this has] reinforced how much my identity is tied to my CF. Because, so many things that I do, are kind of influenced by my CF. Like I have to schedule all of my homework and things like that around my treatment otherwise I don't get my treatment done and then I feel awful and then it's that much harder to do my homework and then that kind of thing. So it really made me realize that, I was now in university and had so much more work to do and so many things to balance how difficult... it could be if you didn't schedule your time properly. So before that I kind of thought about as just like; I'm just a person who has CF and I never really thought strongly about what that would mean in terms of how much it would affect my life until I moved out.

Finally Angella expressed conflicting acceptance and frustration with her body; size and function particularly when compared with assumptions about what 'should' be able to achieve:

Oh, I really like my body! Like, it's not perfect at all, there are lots of things that are weird about it but I really... I have no problem with it. Like I don't know what happened but somewhere between like being a teenager and now, it's like I'm completely okay with it. And there are things that I would change about it, but like only if it was at like literally no risk. And it, like it just doesn't bother me. And like I'll look in the mirror and I like, ok, my body, isn't really perfect but I'm completely fine with it. I'm pretty happy with it, I have no problems with it, except like I wish that it didn't have CF and scoliosis. But besides that, everything else I'm okay with it... But I don't really like being small. Like I hate it when people remind me... like for example lots of girls like it, actually this is another weird juxtaposition! So some girls really hate it when guys pick them up and spin them around because it like reminds them of, they just feel like they might be too fat or whatever. I hate it when guys pick me up and spin me around because I'm really small, and it reminds me that I'm really small and weak and it bothers me, like it really bothers me. Like, I don't like being reminded of that even though I know that I am, it like bugs me, on like a deep level. So, yeah, it's kind of weird, it's a weird relationship... [And] I do feel like it [my body] lets me down... And it's not like, it's definitely not so much, like in the oh, I wish I looked like this department, it's more in like, I feel like I should be able to do more than I can. So like sometimes I'll like, I'll be like, let's say I go for a run or something, not that I do that very much.... But for example, I went hiking up Mount Doug, and in April, and ah, and I was like oh awesome, we're hiking up Mount Doug, but like halfway up, I was just so out of breath and like just coughing and like, I felt fine, like before I got up I felt fine, and it was just kind of a wake up call when you start doing stuff like that. It's like 'oh yeah, right, I forgot that my lungs suck.' With CF, like for me it's like, you just like forget that you have it and then, you're like oh right, my body kind of sucks.

Bodies are changed through illness and body-self unity is disrupted as assumptions of health, beauty, reliability and function are challenged. "Bodies are realized—not just represented but created—in the stories they tell" (Frank, 1995, p. 52). While each experience is unique, each of the women actively constructed empowered accounts of overcoming body weakness and struggle, comparing their bodily strength to others. Another reflection of a narrative script

informing individuals how to 'successfully' live with illness, privileging strength, determination and perseverance to return to health. Their narratives continue to be intimately shaped and constrained by the culturally constructed narrative resources available (Frank, 2009; 2010). Euro Western assumptions about body-mind [dis]-connection and deep messages of what they 'should' know about their bodies or be able to do also informed their connection to their bodies (Wilde, 2003). The internal fighting against the body and illness sheds new light on their illness experiences and identity construction.

As Kleinman (1988) aptly summarizes:

"Chronic illness is more than the sum of the many particular events that occur in an illness career; it is a reciprocal relationship between particular instance and chronic course. The trajectory of chronic illness assimilates to a life course, contributing so intimately to the development of a particular life that illness becomes inseparable from life history" (p. 6), and identity.

The experiences of the participants are vast and varied, and ever changing. Valuable and unique, the accounts shared by participants are powerful, complex and profound. Participants' illness narratives continually contributed to their identity construction in an integral and evolving manner. Finding meaning in their illness they both embrace and resist cultural norms and scripts, embracing incredible flexibility and adaptability in their unfolding identity. The diversity expressed and embraced in their experiences of difference, future planning, dependency, gender and relationships to their bodies, deepens our understanding of how illness impacts their identity construction and suggests numerous implications for both practice and further research.

Chapter 6: Concluding Remarks

This research provides a rich, in-depth exploration of the experiences of identity construction among three young women living with cystic fibrosis. Through engaging in multiple conversations, verbally and visually prompted, these young women were able to voice stories about their identity construction in a personally meaningful manner. Though guided by my questions, the generative nature of our conversations enabled participants to include experiences and thoughts of their own choosing rather than following a prescribed framework. This research provides detailed and thick descriptions of their experiences of illness narratives and identity construction and serves to deepen current understandings of the ways in which these young women with CF construct their identity. This final chapter summarizes key concepts, explores potential implications for practice, education and research, and concludes with a discussion of my own learning through this research process.

Summary

Summarizing the findings in this final chapter is difficult as the experiences are unique to each participant. I do not want to simplify the complexity and diversity of experiences expressed, especially since a central wish from the participants was to be seen uniquely: as dynamic, multidimensional and paradoxical beings, similar and different from their peers. Additionally, as participants, their context and experiences continue to change, so will their stories and unfolding identities. It is imperative to remember the temporal and contextual nature of this study. The following summary is presented tentatively, it is not a finalized interpretation, but remains open and incomplete (Frank, 2010).

The language participants used to discuss their identity construction reflects the mainstream discourse, but their experiences often did not fit the framework provided. They

highlighted the multiple layers of their identity construction, paradoxically strong and weak, sick and healthy, dependent and independent, different and similar. Frequently they presented incomplete pictures of themselves to others, as mainstream understandings of illness, identity and self did not necessarily have the flexibility and freedom to hold their dynamically unfolding sense of self.

Making meaning of illness. As participants navigated the inevitable and ongoing disruptions of their CF symptoms, they constructed narratives of meaning, referencing ongoing positive perspectives, lessons and momentum gained from their illness experiences. The quest to create meaning reflected narrative resources available to them (Frank, 2010), but also demonstrated their resilience and fighting spirit. Indeed, seeing themselves as ‘fighters’ was evident throughout, embracing Marcie’s proactive mantra that “you may have CF, but CF doesn’t have you”. This quest narrative of positive meaning making was further exemplified by Angella and Rachelle’s assertion that given the choice, they would not do their life over again without CF. Their identity without CF is unknown, so while they hope for a cure, they would not change the life they have lived with illness thus far.

Multiple layers. Ever present in the accounts was a sense of multiplicity; there are many layers to each participant’s identity. These layers appeared to respond to various personal and broader societal perceptions and expectations. Sometimes these broader expectations were embraced and shaped individuals sense of identity and at other times they were rejected. Either way they contributed immensely to the construction of self. While their illness is a part of their developing identity, it was important for these young women to be seen as whole and healthy people, highlighting areas of themselves untouched or disrupted by illness and defying the narrow confines of a 'sick person' label. Indeed the limiting perception of sickness, illness and

health in the broader cultural discourse created multiple barriers and frustrations for participants, perpetuating a sense of being different and misunderstood. Limited frameworks of illness and health were felt to be perpetuated by future employers; misunderstanding what it means to be sick, and by their health care team; misunderstanding or showing insensitivity to the meaning of healthy ‘normative’ activities of daily life.

Though feeling different was a familiar sense, they did not feel isolated. Perhaps isolation was mitigated by the rich connection of relationships and community they maintained, both with family and friends living in the absence of CF and online CF community connections. They each noted the importance and profound impact of knowing and connecting with another person living with CF, to both normalize and create solidarity in their shared experience. All of the participants felt their close family and friends shaped how they see themselves and supported them completely.

Flexibility. As participants navigated key identity construction activities such as work and school, and made plans for their future in regards to intimate relationships and vocational aspirations they relied on immense flexibility and dynamism. They seemed to embrace the mainstream stage models of identity development giving importance to these normative tasks but also adapt a fluid, flexible sense of self as they engage in these life events uniquely. Illness disruptions and shorted life expectancy appeared to cause the greatest frustration, though they were still spoken about positively as participants adapted their goals and aspirations to fit the reality determined by their illness.

Gender norms and notions of ‘adulthood’ also influenced participants’ dynamic and flexible identities. While influenced by dominant notions of gender meanings and “adult independence” they each articulated numerous examples of forging their own path, embracing

many socially expected rules and norms but rejecting others. Sometimes this was determined by illness experiences, and at other times it was guided by family upbringing and values. On both levels this influenced the construction and presentation of their flexible identities.

References to their relationship with their body were fascinating and also layered, diverse and dynamic. They talked openly and easily about this relationship, perhaps indicating it is a concept they have previously thought about. The women expressed satisfaction and disappointment with their appearance, noting their small stature makes them closer to the stereotypical ideal female. Feeling trapped by physical limitations and not achieving what they 'should' be able to, as determined by dominant cultural standards, was a common sentiment, as was disgust at being perceived as weak. They used metaphors such as feeling trapped and battling creating a dichotomy between mind and body, but also suggested a greater mind-body connection as they are more tied to their physicality and limitations than others. Rachelle powerfully noted that though her physical limitations may cause some people to exclude her and others with CF from the ideal image of female health and vitality, she rejects this notion, embracing an identity of an active and athletic woman.

Implications

Although this study highlighted the particular, nuanced experiences of a few participants and does not lend itself to generalizing findings to a larger population, its implications still warrant serious consideration. There is much to be learned from the unique experiences explored and the process of inquiry. The potential implications of this research study are broad and diverse, spanning a multitude of venues and disciplines. Considering the audience reading this thesis, I focus next on implications for allied health practitioners, implications for educators in the school of Child and Youth Care, and implications for future research.

Allied health practitioners. Since more people are living longer, fuller lives with chronic illnesses, their time spent in hospital is decreasing and they are accessing services and support from a variety of professionals in addition to front line medical staff. This section is relevant to health care and community professionals supporting young people with CF in a variety of venues and roles for example; CYC practitioners, social workers, nurses, counselors, child life specialists and other allied health professionals.

Each participant expressed gratitude for being involved, both to contribute to research and for the opportunity to think about themselves and their illness differently. They appeared to enjoy and benefit from the conversations, suggesting a potentially therapeutic value to conversations about identity construction. As the dialogue unfolded and they shared experiences, new meanings were constructed and they saw themselves or situations in a new light. That participants were so eager and articulate about their experiences of identity raises questions about how we as practitioners engage, support and interact with young people with CF and other chronic illnesses. They expressed profound frustration when they perceived they were ‘put in a box’, wishing the medical team had a more realistic image of their life outside of illness; the other pieces of their identity. Perhaps engaging in generative conversations about identity and sense of self with young women such as these would help them feel more seen in their totality, less misunderstood, and lead to new insight and possibilities in their identity construction.

This study illustrated how intricately linked the broader social world is to these young women’s unfolding identity. Understanding subtle nuances of ones’ self perception as it is socially constructed shifts attention to factors contributing to this broader social context, and preferred narratives. Throughout this study for example, I have intentionally referred to participants as young women living with CF, and never referred to them as CF ‘patients’ or

people 'suffering' from CF. Though this is a trending shift, much literature exploring the experiences of young people living with chronic illness, and many practitioners in the field still refer to these individuals as CF 'patients', or 'CFers', 'suffering' from the illness. These subtle semantics have the power to perpetuate a specific illness narrative with a negative or disadvantaged perspective of illness, highlighting one aspect of who they are [a patient] as a primary identifying feature. Since each individual is profoundly linked to their social world, and relational processes co-construct the sense of self, the language practitioners and researchers use sets a powerful framework for how the self is enacted. Perhaps a shift in language would enable individuals to perceive more possibilities in how they construct and present this aspect of their identity.

Participants in this research spoke openly and easily about their relationship with their bodies. During adolescence young people have an increasing awareness of their bodily changes and messages of ideal bodies, and develop a complex relationship with their bodies. The participants noted that though they had similar struggles to their peers living without chronic illness, their body-self connection differed from their peers. Rather than look at scores of self-esteem and body image satisfaction, this research suggests talking with young women about their relationships with their bodies as a valid entry point. Research has suggested that individuals with CF may have a difficult relationship with food and body image (Abbott et al., 2000; Tyrell, 2001), exploring the relationship in the manner demonstrated by this study may lead to further insight.

Participants openly expressed fears and challenges regarding delayed puberty, gender expectations, future relationships and career aspirations. Their particular symptoms of CF and shifting life expectancy complicated their experiences of these normative experiences, and

impacted their sense of identity to various degrees. In a culture where identity is still tied to what individuals *do*, or their gender or relationship status, it would be prudent for practitioners to explore the meaning individuals with chronic illnesses make about their experiences in these areas, rather than just recognizing that differences exist.

In the same way, it is interesting for practitioners to consider the tension these women felt at being both independent and dependent women in a culture where independence is promoted as an ultimate goal of successful adulthood. Participants appeared to critically consider whether or not this was a desirable or realistic goal, and embraced flexible perceptions of themselves to achieve independence where they could while maintaining dependence on those they trusted. It would serve practitioners well to facilitate conversations, verbal or visual, with people with chronic illnesses that promote this type of critical reflection and exploration of meanings.

Finally, this study illustrated the importance of practitioners not assuming all experiences of identity and chronic illnesses are similar; many experiences fall outside categories existing within mainstream discourses. While this study and other research illustrates similar challenges and symptoms of CF, the meaning created and impact to sense of self differs dramatically. What some may view negatively may be embraced positively by others, and vice versa, or what is a profound experience for another may hold minimal impact for another, etc. Practitioners would benefit from embracing opportunities that enable individuals with chronic illnesses to express these unique meanings, utilizing stories shared as listening devices to enter into their unique experiences.

Educators. This research is relevant to a range of educators and students in the fields of CYC, social work, nursing, counseling, etc. as these professionals will undoubtedly work with individuals with chronic illnesses in various capacities in hospitals and communities. As a

graduate student in the school of Child and Youth Care (CYC) when considering the implications of this research, I find myself reflecting on CYC instructors equipping students to work with young people with cystic fibrosis and other chronic illnesses. As individuals with chronic illnesses are living longer and healthier lives the interdisciplinary lines are continually shared between traditional hospital based members of the health care team and community support.

A primary theme resounding in this study was the dichotomy created through the dominant perception that sickness and health are two distinct, either-or entities. Participants were both sick and healthy and continually travelled back and forth on the continuum between, and struggled to hold both in their identity simultaneously. When instructors talk about health and illness in the context of CYC, presenting the concept as a continuum may encourage new practitioners to expand their perspective. In turn practitioners may present this possibility to young people they work with, co-constructing new meanings together.

Complicating participants' experience of sickness and health was the socially constructed meaning within their communities, and the language available to describe experiences of health and illness. Culturally constructed and situated roles and expectations surrounding illness behaviours and abilities, and the limitations of language to describe their experiences impacted their perceptions of themselves and how others saw them (Frank, 2010; Gergen, 2009). Not only was the broader community ignorant about CF, the language available to describe illness experiences was unable to accurately depict their realities. Though discussing illness specific experiences is an unrealistic curriculum suggestion, educators would be remiss to not discuss the socially constructed nature of sickness and health, and relational processes of meaning making for individuals living with chronic illnesses.

This study has demonstrated the value of providing opportunities for voicing individual experiences, and sharing narratives. It may be beneficial for educators (within CYC and ongoing professional development) to utilize the expertise of young people living with CF or other illnesses in their in-services, perhaps inviting them to share written or visual images made by young people themselves. This practice could encourage practitioners and educators to think with participants' stories to illuminate their complex realities rather than simplifying or generalizing broad concepts; a helpful approach in both research and practice. As Frank (1995, 2010) and Kleinman (1998) both stress, voicing narratives has rippling impacts, valuable for both the teller and the listener.

Finally, this research suggests that conversations with young people about their developing sense of self, and unfolding identity may be fruitful. Equipping practitioners with a broad perspective and language to discuss identity construction may strengthen their ability to initiate and engage in these generative conversations. This means continuing to move beyond traditional frameworks of understanding identity formation to consider the social construction and unfolding multiplicity of the self.

Future research. Implications for future research can be drawn from both the results of this study and the research design. This study showed that participants were able to think about and articulate their perspectives about their developing identity, beyond the framework of quantitative questionnaires. When given time and space to reflect, they were able to offer much insight into the unique experiences that have shaped them, and how they see themselves. This demonstrates the value and rich potential of continued qualitative research exploring concepts of identity construction among individuals with CF or other chronic illnesses.

Participants shared particular challenges and struggles that are a product of their current socio-cultural climate that individuals living with CF 10 years ago would not have faced. This illustrates the crucial importance of conducting contextually situated and ongoing research, highlighting the voice of young people with CF. It is no longer acceptable to rely solely on health care practitioner or caregiver perspectives to understand the lived experience of CF, it is crucial the insight and expertise of individuals with the illness be sought and expressed in future research.

The uniqueness of participants' experiences further emphasizes the value of conducting illness specific qualitative research, namely research with individuals with CF. Participants frequently stated they felt misunderstood, and the literature consistently suggests their experiences are underrepresented (Jessup & Parkinson, 2010; Pfeffer, Pfeffer & Hodson, 2003). Conducting more qualitative studies that explore the lived experiences of CF may bring more attention to the illness, the diversity between individuals with CF and help individuals with CF see themselves and one another reflected in the literature. Qualitative research approaches offer valuable means to illuminate the particulars in individuals' experiences rather than reducing all accounts to broad generalizations. This type of research enables participants to share their realities in a rich, multifaceted manner, and helps readers pay attention to the nuances and subtleties. As the holder of these stories, I am committed to sharing the findings of this study with the participants. This will be done through sending them a summary report, and informing them when this thesis is posted electronically for public viewing.

Additionally, narrative qualitative research with individuals with chronic illness provides a forum for participants to give voice to their sometimes silenced illness narratives. These illness narratives however, are constrained by the narrative resources available to individuals within

their socio-cultural context (Frank, 2010). It is possible that additional narrative research inquiries providing opportunities for individuals to articulate their unique experiences will diversify the narrative resources available, facilitating greater variety and possibilities available to individuals.

In my study I spoke with individual participants; it would be interesting to conduct group discussions with young people with CF to facilitate generative conversations between participants rather than just between researcher and participant. The meanings co-constructed between participants may be beneficial to explore, possibly leading to rich and divergent findings. While it would be unethical to promote face to face meetings between individuals with CF, the online CF community is very active, and an increasing source of support, connection and information. Future research initiatives may benefit from utilizing this existing online network to facilitate conversation and explore experiences and situated meanings within this community. Tapping into this online network may also be another means to explore the rich experiences of CF and identity within and across different cultures as the cultural context informs the experience.

The experiences of women were highlighted here, while a comparative study between transgendered individuals, men and women was beyond the scope of this inquiry, it would be advantageous to explore in future research. Social constructs of gender influenced how participants' constructed their identity, and undoubtedly would influence young men or transgendered people. Exploring these differences and similarities could be very fruitful and produce a more diverse representation of experiences in the literature.

In this study I utilized photography as a data collection tool. This offered numerous benefits and limitations from which future research may benefit. The value of using images in

research is well documented as they provide an opportunity to transcend the limitations of language, create metaphors, holistically and contextually situate experiences and offer a dynamic mode of participant engagement, (Newbury & Hoskins, 2010a) elements demonstrated in my study. The discussion of the photographs facilitated mutual engagement, where the participants and I engaged in generative, emergent conversation about the images, co-constructing meanings as they emerged (Gergen, 2009). In this sense the inquiry was conducted with participants rather than just about them. Given the under representation and misunderstanding participants have experienced this was particularly meaningful.

The photographs served to compliment the spoken narratives; they successfully moved our conversations to a deeper, metaphorical level, but we still relied on verbal language to express ideas. It would have been interesting to conduct a study that privileged the photographs and utilized language as a support. It is important to recognize however that one participant struggled to visually represent her experiences so the spoken word was very important to her. This demonstrates the value of multiple modalities when collecting accounts, and the difficulty of finding one method meaningful for all participants. Future research in this area would benefit from utilizing multiple methodologies to facilitate the expression of diverse experiences, metaphors and rich contexts.

Personal learning

As the researcher in this inquiry I actively engaged in the research process, influencing each step of the inquiry. I was not an objective outsider, but engaged in a process of meaning making with the participants and consequently have been impacted by our conversations, the analysis and results. As Frank (2010) stresses, the work of stories continues long after the story is told, what I choose to do with the story is my choice but I can never claim it was not heard. I

divide this final discussion into two sections; researcher and practitioner learning. I want to stress however that my learning reaches far beyond these narrow categories, as I am much more than a researcher and practitioner.

Researcher. Engaging in qualitative research was both exciting and challenging. The methodology was as natural fit for me as I appreciate how it seeks to elicit stories of richly detailed experiences within particular socio-cultural climates, and that depth rather than breadth is the focus. The loose unstructured flow of conversations and analysis was a good fit for me as well because I believe this gave the time and space for meanings to be generated in a unique fashion. That being said, I also found the flexibility of the process difficult, even though I embrace the qualitative method I chose as valid and good research, traditional notions of the scientific method influence my own hidden assumptions surrounding good research.

For example, I frequently wondered if I was conducting the interviews ‘correctly’, wishing there was a concrete guide to follow. I felt tension between wanting steps outlining the process to assure me I was doing it ‘right’, and following narrative and dialogical analysis to think with the unfolding stories. I also felt these dueling perspectives as I discussed the findings, feeling pressure to offer concrete simplified, generalizable ‘results’ for practitioners or future researchers, even though this was not a goal of the study. This tension was surprising, as I did not realize I held these assumptions. As with many mainstream assumptions, they ran deeper than I could observe. As a student researcher I appreciated having supportive and knowledgeable researchers and literature to turn to for guidance to navigate this terrain. I believe I chose the most appropriate methodology, and this inquiry process has reaffirmed the value of thinking with the stories, and participating in generative conversations. This expands beyond research, into

therapeutic interactions in practice as a Child Life Specialist, counselor, or another supportive role.

Practice. Listening to the individual stories of experience for subtle nuances of meaning making, and the influence of larger social forces demonstrated the importance of embracing a spirit of curiosity in practice. Just as I struggled with wanting a ‘guide’ in the research process, I can fall into a similar trap in practice and jump in with premature therapeutic plans. Exploring constructed meanings and sense of self with participants over two interviews affirmed the value of creating time and space to have these generative conversations with young people. I think allowing this time enabled the expression of rich and diverse stories of experience, and has challenged me to slow down in practice.

The use of photographs lends itself well to work with young people to elicit symbols and engage in exploratory conversations about subjective experience in an engaging and fun manner. The therapeutic value of photography has been acknowledged throughout the literature, and I look forward to bringing this technique into my practice to move beyond the limitations of language.

Finally, this engaging research inquiry has confirmed my desire to work with young people with chronic illnesses, and engage in work that helps them voice their unique experiences and sense of self. These young people have much to offer and express, and I am excited to continue working with them in ways that facilitate exploration of the relational processes informing their identity. The participants, and all elements of the research inquiry have taught me a great deal, and I hope the work started here will contribute to the literature facilitating diverse perspectives of chronic illness, CF in particular, and identity.

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Appendix A: Recruitment Poster

Are you a female? 16 - 22 years old?
Living with CF?

Want to tell YOUR story?

Kristy Petovello, a graduate student in Child and Youth Care at the University of Victoria, is conducting a study exploring how living with Cystic Fibrosis impacts young women's sense of self, and would like to talk to you!

If you would like to participate or have further questions please contact Kristy.
Thank you!



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Appendix B: Participant Consent Form

Exploring Identity and Illness Narratives: Studying Young Women's Experiences of Cystic Fibrosis

Dear Participant,

You are invited to participate in a study entitled "*Exploring Identity and Illness Narratives: Studying Young Women's Experiences of Cystic Fibrosis*" that is being conducted by Kristy Petovello.

Kristy Petovello is a Child Life Specialist in the pediatric department at the Victoria General Hospital, and a graduate student in the Faculty of Human and Social Development's School of Child and Youth Care at the University of Victoria. You may contact her if you have further questions by email or by phone.

As a graduate student, Kristy is required to conduct research as part of the requirements for a degree in Child and Youth Care at the University of Victoria. It is being conducted under the supervision of Dr. Jennifer White. You may contact her by email or by phone at any time if you have questions.

What is this study about?

The purpose of this research project is to learn more about the experiences of young women living with Cystic Fibrosis. Specifically, Kristy would like to explore how you think living with CF has impacted your sense of self and identity.

Why is this research important?

Research of this type is important because it can help professionals better understand the subjective experience of the impact of CF, and thus better serve young women with CF. Currently the voices of youth with CF are underrepresented in the scholarly literature, this research will create an opportunity for youths' subjective experiences and stories to be told, and help young women see themselves accurately depicted in the literature.

Why are you asking me to take part?

You are being asked to participate in this study because you are a young woman, between the ages of 16-22 and have Cystic Fibrosis. Your perspective is invaluable and she would like to learn from your experiences and expertise. Given the small number of women with CF in this age bracket in Victoria, participants will be accepted into the study on a 'first come' basis. A waitlist will be created once 6 participants have been recruited, these waitlisted individuals will be contacted to participate if someone withdraws from the study.

What is expected of me if I agree to take part in this study?

If you voluntarily agree to participate in this research, the total time requested of your participation is approximately four hours. You will meet with Kristy for a one hour interview, either in person or over SKYPE. Following this interview, she will be asking participants to take one or more photos, in response to the question "who am I?" Participants are asked to refrain from using photographs that identify the faces of other, i.e. family or friends. If participants wish to include certain individuals, they must metaphorically or artistically represent them or obtain written consent. This written consent must also be obtained for any social media postings. It is assumed that participants will use their own cameras for this project, if you do not have a camera one may be loaned to you. These photos will then be used as a point of discussion during a second interview, which will be scheduled approximately 2 weeks later, also lasting one hour. These interviews will be videotaped, only Kristy and Dr. Jennifer White will view this footage when transcribing and analyzing data, consent to this video taping can be given below, and is separate from consent to participation in the study. The interviews will be held at a mutually convenient location such as; over SKYPE, the University of Victoria, a coffee shop or your home and the photography will take place at a location and time of your choosing. Participants will be given a \$25 iTunes gift card as compensation for taking the time to meet.

Will I be inconvenienced if I take part?

If you choose to participate in this study the time required for the interviews, and transportation to and from interview locations may cause you some inconvenience. The requested time commitment is a total of approximately 4 hours.

Are there any risks associated with participating?

If you choose to participate in this study, you may experience some emotional discomfort, stress, embarrassment or fatigue sharing personal information. In order to minimize this, Kristy will try to create a safe and supportive environment. There will be no pressure to continue in the research, you can decide to withdraw at anytime. You will also be invited to take a break at any time during the interview if you feel you need to do so. If you desire further support, you can access support services offered through the Victoria CF clinic.

What are the benefits of my participation?

There are potential benefits to your participation in this study. These include: making a contribution to a gap in existing literature by sharing your personal experiences, which has the potential to impact services provided and add to practitioners' knowledge and understanding of your experiences. There possible personal benefits of your participation in this research such as an opportunity to share your experiences in a supportive setting, potentially gaining new personal understanding.

Will I be compensated for my time?

As a way to compensate you for any inconvenience related to your participation, you will be given a \$25 iTunes gift card following the completion of the final interview. It is important for you to know that it is unethical to provide undue compensation or inducements to research participants and, if you agree to be a participant in this study, this form of compensation to you must not be coercive. If you would not otherwise choose to participate if the compensation was not offered, then you should decline.

Is my participation in this study voluntary?

Your participation in this research must be completely voluntary. If you do decide to participate, you may leave the study at any time without explanation or consequence. It is important that you know, that if you withdraw before the final interview you will not receive your \$25 iTunes gift card. If you decide to withdraw from the study, do you give permission for the continued use of your anonymous data (interview and photographs) in the study?

- Yes, please include my data in the study even if I withdraw part way through
- No, please destroy the data if I withdraw

How will you make sure I still want to participate?

It is important to check with you that you give your permission to take part throughout the entire study. To make sure that you continue to consent to participate in this research, Kristy will verbally ask for your continued consent before starting the second interviews.

Will you be able to know which responses were mine?

Your anonymity will be protected before, during, and after your participation in this study. If you choose to not participate at any time, your anonymity will still be protected. This will be done by removing all identity information from the interview transcripts, and referring to participants by pseudonyms when analyzing transcripts, and reporting findings. This will help minimize the risk that anyone will be able to associate your data (interview transcripts and photography) with you. Due to the small number of young women with CF in Victoria however, a very small risk of personal identification remains, despite the measures taken to maintain anonymity.

Will my responses be kept confidential?

Your confidentiality and the confidentiality of the data will be protected by not using any identifying information in the data. The consent forms and interview transcripts will be kept separately from each other (i.e. not attached to one another). Hard copies of the interview transcripts will be kept in a locked filing cabinet. Digital recordings and accompanying analysis will be kept on a password protected laptop, only the researcher (Kristy Petovello) will have access to this information.

Will I be able to read the results of the study?

It is anticipated that the results of this study will be publically shared with others in the following ways: Thesis and class presentation; presentations to scholarly meetings; published article or chapter; and a summary directly to the participants if they so desire.

Will you keep my responses forever?

The information you've shared during the study will be destroyed once the research has been completed, or up to four (4) years from now. All digital data including; photos, videotapes, and transcriptions will be stored in password protected computer files. All printed data and photographs will be kept in a locked filing cabinet in a locked room. Digital data stored on researcher's computer will be permanently deleted, any printed data will be shredded.

Visually Recorded Images/Data

This information gathered will come from interviews, and discussing photographs taken by participants.

Participant to provide initials:

· I voluntarily consent to the use of my photos brought to the interview for:

Analysis _____ Dissemination* _____

· I voluntarily consent to videos taken of me during the interview for:

Analysis _____ Dissemination* _____

*Even if no names are used, you may be recognizable if visual images are shown in the results.

Who else can I contact for information?

Individuals that may be contacted regarding this study include:

Kristy Petovello

Dr. Jennifer White

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria at: (250) 472-4545 or ethics@uvic.ca and the VIHA Research Ethics office at 250-370-8620 or researchethics@viha.ca.

Your signature below indicates that you understand the above conditions of participation in this study and you have had the opportunity to have your questions answered by the researchers.

Name of Participant

Signature

Date

A copy of this consent will be left with you, and a copy will be taken by the researcher.

Appendix C: Interview Questions

The following questions were created as prompts for the initial conversation exploring participants' constructed identity. Our discussion was emergent so I did not follow the questions as a structured interview. Probes and clarifying questions were used to drawn out complex meanings participants attached to specific ideas and experiences.

1. Tell me about some of the major life events or turning points that have helped shaped how you see yourself.
 - Who was there?
 - What happened next?
 - How does this impact your sense of who you are?
2. Tell me about when you realized you had a diagnosis of CF.
 - What was that like for you? Who was there?
 - How did this impact how you saw yourself?
 - What happened next?
 - How old were you when you were diagnosed?
3. Tell me about a time when you felt you were different from your peers. Similar? What role did your CF play in this experience?
 - What was that like for you? Who was there?
 - What happened next?
 - How did this impact your sense of self?
4. Tell me about your relationship with your body.
 - How did other people influence this perception? Who was there?
 - How do you think your CF influences this relationship?
5. What role, if any, does CF play in defining who you are? How has that changed as you've gotten older?
 - What would other people say?
 - Tell me about times when it plays less of a role. More?
6. How would you define the severity of your CF symptoms right now?
 - Is this similar or different from important people in your life or health care practitioners?
 - How?
 - How does their perception influence how you see yourself?

The following questions were used during the discussion of photographs in response to the question 'Who am I'. Again these questions were not followed in a rigid manner, but the conversation was generative and branched in numerous directions.

1. Tell me about this picture
2. How does this picture tell a story about who you are?
3. Tell me what this says about who you are?
 - a. Is this a side of you that many people see? Who?
4. What made you choose to take this picture?
5. What made you choose this picture to discuss?
6. What is most important about this picture?
7. What story does this picture tell about the role of CF in your life?