

**Negotiating Serious Illness:  
Understanding Young Women's Experiences Through Photovoice**

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By  
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## **ABSTRACT**

Although serious illness is often associated with aging in contemporary society, increasing numbers of young adults are being diagnosed with a variety of serious illnesses. In order to learn more about what it is like to be seriously ill during young adulthood, I completed a qualitative study with ten young women who had recently been affected by a life-threatening or chronic illness. The research was informed by a theoretical approach based on social constructionist and phenomenological principles that recognize that physiological processes such as illness are socially mediated and given meaning within a certain socio-cultural context. Thus, the life course and its corresponding stages are not universal or biologically determined, but rather are social constructions based on socio-cultural factors and the meanings given to certain biological events. This research involved participants between the ages of 20 and 37 from around Saskatchewan who had been affected by a serious illness within the previous three years. The methodological approach that I utilized was interpretive and drew upon phenomenological, feminist, and participatory visual approaches to qualitative research. The young women participated in phenomenological interviews and a photovoice project that explored their 'lived experiences' of serious illness and the specific issues that they faced because of illness. I analyzed the data thematically, incorporating phenomenological concepts of embodiment, temporality, and relationality. Although the interview and photographic data highlighted a range of experiences, the data highlighted several similarities among participants. Foremost, the data revealed that serious illness was highly disruptive for the young women; specifically, participants were required to negotiate disruptions to their sense of embodiment, everyday lives, expectations for the future, and social relationships. Ultimately, serious illness brought about embodied and social experiences that conflicted with how participants had previously envisioned young adulthood and their life course. As such, their experiences of illness had profound implications for their self identity and brought about a complex process of trying to make sense of illness. Based on these findings, I conclude that the young women experienced and made sense of illness within the context of socio-cultural expectations related to age and the life course, as well as gender. I also identify the implications of this research for health care and support services aimed at this population.



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## **Chapter One – Introduction to the Research**

*Living with serious illness and disability can catapult people into a separate reality – with its own rules, rhythms, and tempo (Charmaz 1991, p.4).*

### **1.1 Introduction**

What are the experiences of young adults affected by serious illnesses, and how are their experiences shaped by their life stage? Although research and writing about illness experiences has proliferated in the last four decades, there remains a paucity of research that focuses on young adults with serious illnesses. The lack of research attention on this population may be related to socio-cultural expectations for good health during childhood and young adulthood, and the recent association of serious illness with very old age (Lupton 2003; S.J. Williams 2000). However, a significant number of young adults are diagnosed with serious illnesses each year. For instance, approximately 10,000 young adults in Canada will be diagnosed with cancer each year (Cancer Care Ontario 2006), while three in every 200 Canadian women between age 15 and 24 are affected by an eating disorder (National Eating Disorder Information Centre 2008). Further, chronic illnesses such as multiple sclerosis are often diagnosed between the ages of 15 and 40 (Multiple Sclerosis Society of Canada 2010). As a result, many young adults are required to negotiate a plethora of illness-related issues at a time during which various other life changes often take place in Western societies. Exploring young adults' experiences of serious illness and identifying the issues that arise for this population can raise awareness and guide the development of health care and support services.



In response to the identified gaps in research, I completed a qualitative study that explored the experiences of ten young adult women who had been diagnosed with a serious illness in the past three years. While I come to this topic from a sociology of health and illness orientation, the study builds upon previous research emerging from the disciplines of medicine, nursing, psychology, social work, and anthropology, as well as sociology. Using in-depth interviews and photovoice, I sought to understand participants' lived experiences of illness and how they negotiate illness-related issues. The stories shared by the young adult women provide great insight into what it is like to be ill during young adulthood and how illness disrupts individual and societal expectations surrounding this life stage. Further, participants' stories reveal the imperative for the consideration of social context in the study of illness, as social factors such as age and gender appear to be prominent in how illness is experienced. In the paragraphs and chapters that follow, I demonstrate that illness is not only a physical experience but is experienced and made sense of socially through engagement in social interaction and the beliefs and values of a society (Lorber 1997). As such, I examine participants' illness experiences as the intersection of biological, psychological, and social processes. Further, by contextualizing illness with respect to age and gender, I contribute to the sociological position that experiences of illness and the meanings assigned to them are socially constructed, as is the concept of the life course.



## **1.2 Sociological Studies of Health and Illness**

In order to provide a preliminary understanding for this research, I briefly outline some of the key principles and debates underlying the sociological study of health and illness. Beginning in the 1950s, sociologists paid more attention to the social aspects of health and illness. The initial focus was on the management of ill bodies and the social structures that regulate people's bodies. In particular, Parsons (1951) developed the concept of the 'sick role', a social role that enabled individuals to be exempt from their duties as contributing members of society while they sought medical care (Lupton 2003, p. 7). Illness was viewed as legitimate deviance in the event that it was recognized by a medical professional and affected individuals endeavoured to return to their previous 'normal' state of health (Ibid). Parsons' concept provides an early example of the characterization of illness as a social experience by recognizing that, in modern (Western) society, illness is constructed to a large extent through the doctor-patient encounter, and that there are social expectations surrounding health and illness (Ibid).

Parsons' functionalist perspective can be criticized for oversimplifying health and illness by portraying them as exclusive categories between which individuals can easily move (i.e., healthy – sick – healthy). Thus, he emphasized the curative ability of the medical profession, which neglects the complex experiences of individuals with chronic and terminal illnesses in contrast with those affected by illnesses where the line between sickness and health is more easily drawn because of their treatability (Frank 1995). Further, Parsons' theory propagates the assumption that all individuals have equal access to the sick role, thus failing to recognize the influence of social factors on health and illness experiences (e.g., Werner & Malterud 2003). Despite these criticisms, Parsons'



work provided much of the initial groundwork for the study of health and illness in contemporary sociology.

Sociological writing on health and illness since Parsons' time has acknowledged the influence of social factors on interactions related to health and illness. For example, scholars such as Freidson (1970) and Illich (1976) drew attention to the conflict inherent in doctor-patient relationships due to the power and influence possessed by the medical profession in modern society. Thus, medical professionals were viewed as having responsibility for determining the legitimacy of illness, which ultimately led to a number of social behaviours being classified as illness ("medicalization") and requiring medical expertise (Lupton 2003, p.9). Further, the medical profession's jurisdiction over defining illness endowed them with moral authority not unlike that previously held by religious officials (Turner 1984). Thus, certain individuals or groups could be deemed 'ill' and in need of care (and/or protection) from the medical profession (Ibid).

More recently, as a result of the influence of poststructuralist and postmodern social theorists such as Foucault, and feminist theorists such as Butler and Haraway, sociological focus has shifted to how health and illness are socially constructed (Frank 1995; Lupton 2003; Turner 1984). Specifically, social constructionist approaches examine how health and illness are constructed through language and experienced within social contexts; in other words, how our bodies are 'inscribed' with discourses related to health and illness in a given society (Ibid). Thus, the physiological aspects of health and illness are viewed as less significant than the meanings assigned to them in social interaction and different discourses. Although social constructionism has generated important contributions to sociology, critics argue that this theoretical orientation



portrays all knowledge as relative and equally valid, including that put forth by social constructionists, and therefore neglects the material realities of the social world (Ibid).

In response to critiques of social constructionism, Turner (1984, 1992) and Frank (1995), along with a handful of other scholars, advocated for a greater inclusion of the biological or material body in social research on health and illness. In doing so, these scholars avoid portraying the body<sup>1</sup> as a completely discursive construct in favour of exploring how our physical bodies are experienced in social ways. Turner (1992) provides a particularly useful perspective that integrates social constructionism with phenomenology in order to acknowledge both the material and discursive aspects of the body. In particular, Turner's approach draws on the phenomenological notion of embodiment, or the body as it is lived and experienced in conjunction with the self, which I elaborate upon in Chapter Three.

A similar perspective is also articulated by Lupton (2003), who recognizes that while “experiences such as illness, disease and pain exist as biological realities... such experiences are always inevitably given meaning and therefore understood and experienced through cultural and social processes” (p. 14). Therefore, these scholars acknowledge the physicality of our bodies in addition to emphasizing that one's physical body cannot be experienced or made sense of outside of psycho-social processes. The greater attention being paid to the body in social research, as well as the increased interest

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<sup>1</sup> The term ‘the body’ is commonly adopted by sociologists (i.e., the sociology of the body) to refer to the biological qualities or embodied nature of individuals, which includes a plurality of bodies rather than implying a singular experience or essentialist nature of the body. For example, the term is used by Turner in his seminal work *The Body and Society* (1984). According to S.J. Williams (2006), the body refers to ‘the lived body’ - “the moving, thinking, feeling, pulsing, body” - thus incorporating the phenomenological emphasis on the interconnection between the mind and body (p.10).



in illness narratives (discussed in detail in Chapter Three), has contributed to a proliferation of research on individuals' perspectives and experiences of health and illness, and how they are shaped by social structures and discourses.

In summary, these sociological studies of health and illness, among others, provide the context in which I carried out the research reported in this dissertation. My theoretical orientation draws upon elements of social constructionism and phenomenology, particularly as theorized by Turner (1992) and Lupton (2003), in an effort to highlight how illness is a social experience as well as a physical one. Specifically, I incorporate both the recognition of the socially constructed nature of illness experiences, as well as the phenomenological recognition of the biological body through which the social world is experienced. As such, I explore how serious illness is experienced and made meaningful from the points of view of young adult women in order to demonstrate how social constructions of illness and the life course inform their understanding of their embodied experiences. In doing so, I provide evidence of how social factors, such as gender and age, contribute to how illness is experienced and understood.

### **1.3 Why Research Experiences of Illness?**

Broadly speaking, research on individuals' stories of illness can yield a better understanding of such experiences and the socio-cultural context in which they occur. Additionally, illness narratives provide insight into the challenges that many individuals face, as well as how these challenges are dealt with and made sense of (Kleinman 1988).



Therefore, stories of illness serve as a way to educate others as to what it is like to be ill, which can benefit those facing similar life events and those involved in caring and supporting ill individuals. For ill individuals themselves, formulating their experiences into a story may generate a greater sense of coherence or meaning (Good 1994) or restore the voice that they lost because of illness (Frank 1995). Thus, research on stories of illness can be beneficial for ill individuals, family, friends, health care and support providers, and members of the broader society, just as participation in such research may be meaningful to those involved.

The stories told by participants in this study reveal the issues that arose as a result of serious illness and provide insight into: embodied experiences of illness, the processes of diagnosis, treatment and coping, the negotiation of social support and care, and how attempts to make sense of illness on a personal level occurred within a broader socio-cultural context. Although no two experiences of illness will be the same, certain aspects of participants' stories may be of relevance to other young women facing illness or similar traumatic events. Therefore, participants' stories may benefit other young adults by providing inspiration, advice, and/or strategies for coping with illness, which is particularly important because young adults may have little prior experience in dealing with ill health (Politi, Enright, & Weihs 2007). The identification of specific care and support needs in participants' stories of illness also has implications for health care and support services, including the development or improvement of specific services for this population. Further, participants' stories of illness enable the examination of how sense is made of being seriously ill during young adulthood with respect to socio-cultural ideals



related to illness and the life course, which emphasizes the social component of illness experiences.

While the study of illness narratives is important from sociological and health care standpoints, this research also has personal meaning. As a young adult, I know firsthand the transitions and changes that are common to this life stage for those belonging to the dominant majority in Western societies. Thus, my personal biography provides me with implicit knowledge of what it is like to be a young adult in Canadian society and the corresponding challenges. Additionally, I am aware of socio-cultural expectations for good health during young adulthood, as well as other expectations for this life stage. This led me to ask what it is like for young adults affected by illness whose experiences may not correspond to socio-cultural expectations, and specifically how they negotiate challenges related to illness amidst the transitions common to young adulthood. Hearing and seeing participants' stories has been a privilege and has generated profound admiration for the strength and resiliency shown by these young women. I believe that their stories of illness offer both inspiration and practical insight into the ongoing processes of coping and making sense of illness, and will be of interest and benefit to a variety of audiences.

#### **1.4 Purpose, Research Questions and Thesis**

The purpose of this research was to gain a better understanding of the experiences of young adult women with serious illnesses. I define 'serious illness' as either a life-threatening or chronic illness with an unpredictable trajectory that has significantly



affected an individual's life and well-being. I chose to focus on young adults' experiences of illness: because they often go unacknowledged, the rates at which young adults are affected by various illnesses are increasing, and because being ill during this time of life is often unexpected and contradicts socio-cultural expectations for this life stage in contemporary western society. Thus, I wanted to find out what it was like for young adults to be seriously ill at this time in their life, and how they negotiated and understood the issues that illness introduced into their everyday lives and futures. Although some existing research has focused on young adults with serious illnesses, there is a notable absence of studies that examine the social experience of illness from young adults' perspectives, or look for similarities and differences in experience for young adult women across different serious illnesses. As such, my research contributes to this gap by offering a better understanding of what it is like to be seriously ill during young adulthood for young women.

The research questions that guided this study were:

- 1) What are young adults' experiences of serious illness and the specific issues they face?
- 2) How are young adults' experiences of serious illness shaped by the timing of their illness diagnosis?

These research questions guided in-depth interviews and a photovoice project with ten young adult women affected by serious illness.<sup>2</sup> My analysis of the interview and photovoice data revealed that how participants experienced and made sense of their

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<sup>2</sup> Although both young adult males and females were invited to participate in the research, very few males responded to recruitment advertisements, none of whom fit the inclusion criteria. I discuss factors that contributed to the absence of male participants in Chapter Three.



illness was related to their age and gender. Specifically, the women often communicated feelings of being different than ill older and younger adults, or other healthy young women. Therefore, I argue that social factors must be accounted for in the provision of health care and support services in order to ensure that the needs of different populations are met.

## **1.5 Outline of the Dissertation**

In this first chapter, I provide a brief overview of the research and its background in the sociology of health and illness in order to situate the research in the broader discipline. I also describe the purpose of the research, the research questions guiding the research, and the thesis statement.

In the second chapter, I elaborate on the theoretical and empirical foundations of the study by reviewing the existing literature related to young adults and serious illness. First, I discuss the social construction of illness and how the timing of illness affects how it is perceived and experienced. Next, I highlight existing literature on young adults' experiences of serious illnesses, which incorporates research from a variety of different disciplines. In doing so, I outline the current state of knowledge on young adults' experiences of serious illness, as well as gaps in knowledge.

Chapter Three offers an overview of qualitative inquiry and illness narratives, followed by a description of my interpretive methodological approach that incorporates phenomenological, feminist, and participatory principles. In these sub-sections, I highlight the theoretical underpinnings of each component of my methodological



approach and their compatibility with one another, thus further explicating the theoretical foundations of the research. This discussion is followed by an outline of the research design, including how participants were recruited and selected, and the others steps involved in carrying out the research. I then conclude the chapter by discussing pertinent issues related to ethics, credibility, and data analysis.

Chapter Four is composed of summaries of the stories shared by each participant. These stories provide the reader with an introduction to the participants and the chronology of their illness experience. These summaries highlight the key themes that emerge as significant in each participant's story of illness, which are then discussed in a cross-sectional manner in Chapters Five, Six and Seven.

In Chapter Five, I present the themes that emerged across the data with respect to young adults' embodied experiences of illness. The chapter is divided into broad themes, which are related to: discerning and learning about illness, and the disruptions brought about to everyday life and the lived body. These two broad themes are divided into several sub-themes that illustrate the issues that the young adult women faced/are facing because of the physical implications of illness. Throughout the chapter, I discuss the themes in relation to the existing literature on this topic and highlight similarities or differences among participants.

In Chapter Six, I highlight what the data reveal about being ill during young adulthood, and how participants' experienced serious illness as disruptive in relation to their stage in the life course. I also discuss the need to negotiate social support and



relationships as a result of illness. Once again, I situate these findings in the existing literature on young adults with serious illness.

Finally in Chapter Seven, I conclude the dissertation with a final discussion of how participants made sense of illness, which is both a distinct theme and summation of the themes discussed in Chapters Five and Six. In addition, I summarize the findings of the research with respect to existing research and offer implications for health care and support services. Next, I offer methodological reflections, followed by a final conclusion.



## **Chapter Two – Contextualizing the Research: Theoretical & Empirical Foundations**

*Growing understanding may or may not be accompanied by physical healing, but it will bring comfort, and an awareness of our connectedness, a lessened fear of death, and a sense of and purpose in life* (Cunningham 1993, p.68-69).

### **2.1 Theoretical Background**

Although age is typically thought of in biological terms - our proximity to birth or death - age is very much constructed through the social practices of a society (Matthews 1979, cited in Holstein & Gubrium 2007, p.338). Namely, age exerts a powerful influence on how we understand ourselves and experience the social world (Hockey & James 2003). The categorization of ages into life stages that form the life course provides societal prescriptions for when life events should or should not take place; thus, the social construction of the life course distinguishes what are considered ‘normal’ experiences for individuals and when they should typically occur in a given society and time period. Exley and Letherby (2001) suggest that, despite that variation that occurs among individuals’ lives, there remain some life events that contradict expectations for certain ages or life stages. For example, one life event that is experienced as disruptive to life course expectations in contemporary western society is the diagnosis of a serious illness prior to old age (see for example, Bury 1982), as the majority of individuals expect to live into old age (Bury & Wadsworth 2003; Kellehear 2007). This idea is elaborated on in this section on the theoretical background to this research, as well as being central to the exploration of young adults’ experiences of serious illness.



The following sub-sections outline the theoretical background that informed this research on young adults' experiences of serious illness, which corresponds to the theoretical underpinnings of my methodological approach that I discuss in Chapter Three. Specifically, I propose that the life course, while often linked to biological occurrences, is a social construction of the 'ideal' course an individual's life should take in a given society. Thus, ideals regarding the life course are greatly influential on individuals' thinking about their identities and how they make sense of their experiences. As such, the timing of illness is crucial to how individuals' experience and make meaning of their experiences. In the following paragraphs, I outline my justification for viewing the life course as socially constructed, specific dominant social narratives related to young adulthood, and evidence of the impact that the timing of illness can have on individual's experiences.

#### *2.1.1 The Life Course as Socially Constructed*

The term 'life course' refers to the notion that individuals' lives follow 'natural' patterns of progression through time (Clausen 1986, cited in Holstein & Gubrium 2007, p.335). More simply, the life course can be thought of as the life stages that individuals typically experience between birth and death. However, social perspectives on the life course view it as a reflection of the attribution of social and personal meanings to individuals' biographical progression through time (Hagestad 1990). Furthermore, scholars adhering to a constructionist approach view the life course as socially constructed in that the ideals or expectations associated with age arise from the social



context in which they occur and are not an inherent part of aging. For example, Burman (2008) proposes that expectations for individual development promoted by developmental psychology can be linked to efforts to maintain social control and the marginalization of certain groups and populations beginning in the mid-19<sup>th</sup> century, as opposed to reflecting a scientific explanation of the development process.

As such, aging can be thought of as a social process rather than a purely biological one (Hockey & James 2003). This belief acknowledges that there are various physiological processes involved in aging, but also that the experience of these processes is social mediated and the meanings assigned to them are not universal. Similarly, Bury and Wadsworth (2003) purport that, while biology sets limits to human endeavours, “health and ageing take on distinct features that cannot readily be reduced to biology” (p.111). Therefore, biological processes such as menarche may influence the social construction of life stages; however, the social definitions associated with certain ages form the basis of specific life stages. For example, in Western society, legal age limits often demarcate ‘adulthood’ rather than physiological processes, such as the age at which an individual can vote or purchase alcohol and cigarettes, which is somewhat arbitrarily defined by political and legal authorities.

Furthermore, different stages in the life course are defined in correspondence to the social roles available to individuals of certain ages. Thus, the division of the life course into stages reflects the role expectations that individuals are socialized into viewing as ‘natural’ in a certain culture (Holstein & Gubrium 2007). As individuals are thought to be embedded in their socio-cultural contexts (Baddeley & Singer 2007), the differentiation of specific life stages and the associated role expectations will vary among



different societies. For example, young people from different societies may gain independence from their families of origin at different points in their lives, depending on the society that they live in and factors such as physical maturity, the duration of their formal education, or the timing of their move into paid employment (see, for example, Hockey & James 2003, p.24-27 for a discussion of rites of passage in different cultural contexts). It is crucial to recognize the variations that exist in how the stages of the life course are defined, which provide evidence of their socially mediated nature. This means that the life course can be thought of as “a series of life-long alterations of roles and self-definitions that proceed with age” (Holstein & Gubrium).

Such a characterization of the life course reflects social constructionist principles; specifically, that meaning is not inherent in objects or events but instead is constructed by individuals through language use and social interaction (Berger & Luckmann 1966, cited in Holstein & Gubrium 2007, p. 336). Often when individuals experience unfamiliar situations, they seek to draw upon existing meaning structures, also referred to as ‘frames’ or ‘typifications’, to make sense of what is occurring (see, for example, Ellis 2002, and Rehorick 1986). Holstein and Gubrium refer to these meaning structures as ‘interpretive resources’ that are formed out of the “well-known, culturally shared common sense categories and ideas” that make up the social world (p. 344). By drawing on ‘interpretive resources’, individuals reproduce meaning structures and reinforce their legitimacy. Thus, others who find themselves in similar situations may also draw upon similar meaning-making resources in order to understand their experiences. As such, meanings regarding certain experiences become entrenched in a society and emerge as ‘dominant social narratives’ or ‘cultural scripts’ (Lee 2001; Seale 1998).



According to Foucault (1980), the dominant knowledge discourses of a society structure the lives of its members (cited in Murray 1997, p.14). Whereas religious institutions formerly controlled the production and dissemination of knowledge in the past, scientific knowledge, and particularly medical knowledge, now composes the dominant discourse in contemporary Western society (Turner 1987). As a result of the power held by scientific and medical institutions, individuals may willingly accept dominant discourses as fact rather than social constructions resulting from power relations. Lee (2001) furthers the claims of Foucault and Turner by proposing that theories about human development, particularly ones that claim to explain universal biological or psychological processes, form a 'dominant social narrative' in Western society (p.284). In particular, developmental theories provide expectations regarding how individuals should progress as they age, thus prescribing ideals for individuals by which they are deemed to be 'normal' or 'deviant' (Ibid). As such, individuals experience their own lives and expectations for the future within this 'dominant social narrative'.

The transition from childhood to adulthood is particularly fraught with expectations in contemporary western societies. Hardoff and Chigier (1991) propose that this transition involves: consolidating personal & sexual identity, establishing relationships external to the family, achieving independence from the family of origin, and finding a vocation (cited in Packham 2004, p. 7). Other scholars have suggested that adolescence and young adulthood customarily involve: shifting relationships with parents, leaving the family home, establishing a career, forming new relationships with friends and sexual partners, getting married, raising a family, and becoming increasingly independent, including taking responsibility for one's health (Grinyer 2007; Lynam



1995). Such transitional activities often take place over the course of several years, and are not necessarily a linear or coordinated process (George & Hutton, 2003, cited in Grinyer 2007, p. 5). Thus, individuals in their teenage and young adult years will likely be at various points in this process, with some being quite independent and others continuing to rely on their family of origin for support. Despite being portrayed as essential activities to the fulfillment of developmental and life course goals, many of the events associated with young adulthood and the transition from adolescence are arbitrary and could occur at different times in life, such as the establishment of independence from the family of origin earlier in life or establishment of a long term partnership later in life.

Grinyer (2007) proposes that the occurrence of an unexpected life event such as the diagnosis of a life-threatening illness can cause significant disruptions to this transitional process. As a result, young people may struggle with progressing through this transition and fulfilling their own and others' expectations for young adulthood. In particular, young people may see their illness as moving them away from the 'dominant social narrative' regarding this life stage in contemporary western society, making it difficult for them to reconcile being ill with their young adult identity. In addition, the recognition that their life course has strayed from what is expected may introduce various losses, as the individual realizes the potential implications of their illness. The following discussion elaborates on the influence that the timing of illness has on how illness is experienced.



### 2.1.2 *The Timing of Illness*

Similar to ageing, experiences of health and illness are also mediated by the socio-cultural context in which they occur. According to Lorber (1997), illness goes beyond the experience of bodily dysfunction to encapsulate the social, emotional and physical disruptions to individuals' lives. As such, illness is socially constructed in that the experience of being ill plays out in social interactions, and is affected by social characteristics such as age, gender, class, race, ethnicity, and sexual orientation (Ibid). Additionally, the experience of illness is influenced by socio-cultural beliefs about health and illness. In particular, the meanings assigned to certain illnesses in a society are often highly influential on the extent that illness disrupts an individual's social world (see, for example, Sontag 1978). In this section, I expand on the idea that illness is socially experienced with particular emphasis on how the timing of illness impacts individuals' experience and understanding of it.

Drawing on the historical work of Thane (2000), Bury and Wadsworth (2003) propose that living until old age is not solely an experience of modern society, as some individuals living in the 17<sup>th</sup>, 18<sup>th</sup> and 19<sup>th</sup> centuries escaped life-threatening infections that were commonly responsible for death at a young age; however, these scholars argue that the defining characteristic of contemporary society is that the majority of individuals will live to be 60 years of age or older (Ibid), if not 80 or 90 (Kellehear 2007). As such, longevity is an expectation held by many. In particular, public health measures to improve housing, nutrition, income and hygiene increased life expectancy in the mid-19<sup>th</sup> century, while improved science and medical practices in the 20<sup>th</sup> century have contributed to much fewer deaths early in life resulting from infectious disease and



childbirth (Lupton 2003; Moseley 2004, cited in Kellehear, p.201). Accordingly, experiences of illness and aging occur within temporal and societal contexts. In other words, there is no inherent meaning in the physical experience of illness, but rather individuals make sense of illness with respect to the socio-cultural expectations of a certain time and place.

Although the onset of illness is neither easily managed nor desired by most individuals, the timing of illness can contribute to variance in how illness is experienced and understood. S. J. Williams (2000) proposes the idea of the ‘normality’ of illness for some individuals, referring to the belief that illness or health problems are to be expected because of their class, age, or other social variables (p.50). To support this idea, this scholar draws on empirical research by Pound et al. (1998), which found that individuals in their 70s, 80s, and 90s may be better prepared to deal with hardships such as illness than younger individuals because of their life stage (cited in S.J. Williams, p.51). Further, some illnesses such as cancer may be expected by older adults because the major risk factor is age in that it compounds other risk factors, such as exposure to carcinogens (Kellehear 2007). Thus, older individuals may find the diagnosis of a serious illness to be less distressful because it is more expected, even anticipated, during this life stage. Subsequently, the diagnosis of a serious illness in young adults may be especially problematic because it contradicts widespread beliefs about youth, health and longevity in contemporary society (Hilton, Emslie, Hunt, Chapple, & Ziebland 2009; Exley & Letherby 2001). Therefore, both individual and socio-cultural expectations for certain life stages may play a role in how illness is experienced and understood.



Older individuals may also be better equipped to cope with illness than younger individuals because of prior experience with illness, as was proposed in a study of women coping with breast cancer (Politi et al. 2007). Further, research has found that older individuals may be more likely to find meaning in illness because of this greater experience coping with illness and fewer demands on them to fulfill former roles (Scioli, McClelland, Weaver, & Madden 2000). Thus, older individuals' life experiences and accomplishments may contribute to greater coping ability in comparison to younger individuals who have not yet had the opportunity to achieve many of society's common developmental goals. For example, in contemporary western societies, younger individuals may be yet to establish their careers, intimate relationships, families, and individual identity outside the family of origin (Petersen, Kruezek, & Shaffner 2003). Therefore, there are various factors that may contribute to the perception of illness as less problematic and more expected for older individuals when compared to younger individuals.

Furthermore, in contemporary Western society, younger individuals may experience the onset of a life-threatening or chronic illness as implying 'premature aging' (Singer 1974, cited in Bury 1982, p. 171) because the illness diagnosis "mark[s] a biographical shift from a perceived normal trajectory through relatively predictable chronological steps, to one fundamentally abnormal and inwardly damaging" (Bury, p.171). Accordingly, becoming ill may be profoundly shocking and disruptive to younger individuals because of its unexpectedness, and because it may prevent the fulfillment of social roles and expectations associated with their 'aged identities' in contemporary society (Hockey & James 2003). In addition to experiencing illness as a departure from



the socially-defined, 'ideal' life course, younger individuals may experience illness as a threat to their own expectations for their life stage. Therefore, illness may result in the need to re-examine taken-for-granted assumptions about the social world and re-formulate one's self identity to account for a changed health status (Bury; Charmaz 1991). For young adults in particular, it may be difficult to reconcile being seriously ill with expectations regarding their life stage, as young adulthood is typically characterized as a time when positive life events occur, such as "finishing one's education, getting a first job, getting married, having a first child" (Baddeley & Singer 2007, p.183). Finally, young adults may also struggle with their perceived 'premature aging' due to illness because aging is typically devalued and therefore undesired in contemporary Western society, especially for women (e.g., Slevin 2010).

As well as causing disruptions to everyday life and plans for the future, the diagnosis of a serious illness may be the first occasion on which individuals confront their mortality. For younger individuals in particular, the realization of mortality as a result of serious illness may be especially problematic because becoming ill and dying at a young age conflicts with current cultural scripts regarding 'normal' progression through the life course. This claim is supported by research performed with low-socioeconomic status palliative care patients with cancer, many of whom experienced their life-threatening illness and impending death as deviant because it was "off-time" with societal standards given their relatively young age (B.R. Williams 2004). Specifically, dying before average life expectancy is problematic because it contradicts current socio-cultural expectations for the life course. In addition, Exley and Letherby (2001) describe other factors that contribute to 'dying prematurely', including dying prior to one's parents,



while still economically active, or with young children at home. Thus, ‘dying prematurely’ refers to dying that differs from societal ideals about how and when death should occur, namely from ‘natural’ causes in old age in contemporary society (Kellehear 2007).

Existing literature also suggests that members of contemporary western societies commonly perceive ‘dying young’ to be unjust or abnormal (Chasteen & Madey 2003; B.R. Williams 2004). In particular, the death of younger individuals prompts other people to mourn the loss of the individual’s future and potential contributions to society (Jecker & Schneiderman 1994). In accordance, the death of older members of society is often viewed as less tragic than the death of younger members (Chasteen & Madey). These statements imply that the death of older individuals is perceived as more acceptable in comparison to the death of younger individuals, as older individuals have already had an opportunity to achieve their goals and contribute to society. Kellehear (2007) furthers this point, suggesting that early or premature death is perceived as shameful specifically because the young are economically and politically valuable to society. This differential view of death based on age brings up a number of issues regarding individuals’ responsibilities to avoid dying young and has implications for access to medical services (Jecker & Schneiderman).

Taken together, what the above mentioned research suggests is that young adults are likely to experience the diagnosis of a serious illness differently than older adults. Foremost, the existing literature highlights that there are distinct expectations associated with different life stages, or ‘aged identities’ (Hockey & James 2003). Thus, young adults may perceive a diagnosis of serious illness as contradicting their own and socio-cultural



beliefs about youth and health, as well as introducing the possibility of dying before what is considered the 'right time' (Exley & Letherby 2001; Kellehear 2007). Because of the typical unexpectedness of illness and their possible inexperience in coping with illness, young adults may find a serious illness diagnosis difficult to negotiate and make sense of in comparison to older adults. In addition, young adulthood is often the time when many important life events occur, meaning that serious illness may disrupt young adults' ability to establish themselves in new roles and/or fulfill existing responsibilities. Thus, young adults may suffer disruptions and losses that are unique to individuals of other ages or life stages.

### *2.1.3 Summary*

The above discussion demonstrates that the timing of illness has a profound impact on how individuals perceive and experience serious illness and the possibility of dying. Nonetheless, it is important to recognize that the characterization of illness and dying as being part of the aging process, and thus contradictory to young adulthood, is socially constructed; namely, socio-cultural expectations regarding the life course are not based on a universal version of human development but rather patterns that have been deemed to be typical in a certain society. Consequently, young adults may experience the diagnosis of a serious illness as disruptive because it threatens their ability to follow a 'normal' life trajectory and fulfill certain expectations for their life stage. As such, there is a need to acknowledge that experiences of serious illness are mediated by the social context in which they occur, because social interaction and factors such as gender, age, class, race, and ethnicity influence how we understand such experiences. In the following



section, I offer a critical assessment of the existing literature on young adults affected by serious illness as a foundation for my research and analysis.

## **2.2 Critical Assessment of Existing Research on Young Adults with Serious Illnesses**

Although research on illness has proliferated in recent years, research focusing specifically on young adults' experiences of serious illnesses is relatively scarce. However, various statistics show that many young adults are affected by serious illness. For example, approximately 10,000 individuals between the ages of 20 and 44 are affected by cancer each year in Canada, and cancer is the leading cause of death for young adult women and the third leading cause of death for young adult men in Canada (Cancer Care Ontario 2006). The diagnosis of chronic conditions such as multiple sclerosis also commonly occurs during the young adult life stage (Zwibel 2009). Further, mental illnesses such as depression and eating disorders also affect young people, with the highest risk for anorexia being among females aged 15 to 30 (Robinson 2000). Empirical evidence shows that all of these illnesses can be detrimental to individuals' quality of life and longevity. Thus, these statistics illustrate that being diagnosed with a serious illness during young adulthood is a distinct possibility. Despite substantial evidence that many young adults are affected by serious illness, consistency is lacking in how young adulthood is defined, and the experiences of young adults who are ill are not fully understood. The following section critically examines the definition of 'young adult' in the existing literature. The remaining sections of the chapter then focus on empirical research and what is currently known about young adults' experiences of serious illness.



### *2.2.1 Defining ‘Young Adult’*

Despite evidence that young adults are being diagnosed with serious illnesses, there has been little focus on young adults as a unique population. Existing research that has included young adults has tended to be on young adults with cancer, and within this literature the definition of ‘young adult’ has varied. Research studies that have focused on other types of illnesses also draw upon varied definitions of ‘young adult’, and often combine this population with younger individuals. Table 1 provides a selection of current definitions and highlights the variation in age range and how age range is determined.



Author(s)/Organization	Type of Illness	Population label	Age Range of Participants (years)	Justification for Age Range
<i>Bleyer, Viny &amp; Barr (2006)</i>	Cancer	Young adults & adolescents	15 to 29	Most cancers that occur before age 30 are spontaneous & unrelated to environmental or genetic factors
<i>Cancer Care Ontario (2006)</i>	Cancer	Young adults	20 to 44	Ages chosen span from the end of adolescence to the time when menopause typically changes the cancer profile in women
<i>Coyne &amp; Borbasi (2006-7)</i>	Breast cancer	Younger women	Under 50	Women of childbearing age/ premenopausal women; women who must balance multiple roles (i.e. childrearing, household tasks, work)
<i>Dunn &amp; Steginga (2000)</i>	Breast cancer	Young women	No specific age range recruited, participants aged 31 to 47	Women who have young children, are premenopausal, &/or are of childbearing age; women who self-identify as young or have life situations related to being 'young'
<i>Grinyer (2002, 2007)</i>	Cancer	Young adults/ young people	15 to 26	Individuals in the transitional stage between childhood & adulthood (somewhat arbitrarily defined as teenage & young adult years)
<i>Kyngas et al. (2000)</i>	Cancer	Young adults & adolescents	16 to 22	Transition period from dependence to independence when new social & emotional roles are adopted
<i>Lynam (1995)</i>	Cancer	Young adults	19 to 30	Period of life when individuals make many important decisions regarding relationships, career, family
<i>Miedema, Hamilton &amp; Easley (2007)</i>	Cancer	Young adults	20 to 35	Age 35 marks the threshold age for non-epithelial cancers; the establishment of independence, relationships, & employment commonly occurs during individuals' 20s & 30s
<i>Packham (2004)</i>	Juvenile arthritis	Young adults	15 to 24	Individuals involved in the physical, emotional, and social transition from childhood to young adulthood
<i>Pugh et al. (2005)</i>	Epilepsy	Young adults	18 to 40 (compared to 41 to 64, & 65 & older)	Age ranges are based on developmental theory & military cohort effects

Table 1 – Definitions of 'Young Adult' in Recent Studies



As shown in Table 1, the ages of participants in studies of young adults and serious illness range between 15 and 50 years old with little consistency at either end of the range. Furthermore, the selected age ranges vary as to whether they are based on biomedical or social factors. For example, some cancer researchers demarcate the upper boundary of young adulthood at age 30, 35 or 44 because these ages are viewed as being the point at which certain types of cancer become more prevalent (i.e., spontaneous vs. genetic or environmental aetiology, epithelial vs. non-epithelial) (Bleyer et al. 2006; Cancer Care Ontario 2006; Miedema et al. 2007). Other researchers apply the label ‘younger women’ to individuals who are of childbearing age or premenopausal when diagnosed with breast cancer, thus using physiological markers to determine who is considered ‘young’ (Coyne and Borbasi 2006-7; Dunn & Steginga 2000). However, these scholars also acknowledge that social markers contribute to their definition of ‘younger women’, stating that younger women are more likely to have dependent children and take on multiple social roles in the private and public realms in comparison to women over 50 (Coyne & Borbasi). Young adulthood has also been characterized as the time at which individuals make decisions regarding relationships, employment, and children, and transition from dependence on family of origin to independence (Kyngas et al. 2001; Lynam 1995; Miedema et al.; Packham 2004). Thus, existing research has drawn upon both biomedical and social factors in defining ‘young adulthood.’

In addition to variance in how young adulthood is defined, existing studies also examine young adults with serious illness alongside both younger and older individuals. While certain authors cited in Table 1 identify age 15 as the lower boundary of young adulthood, many other researchers have grouped young adults and adolescents into one population that includes individuals as young as 12 (e.g., Bergeron, Poirier, Fournier, Roberge, & Barrette 2005; Kameny



& Bearison 2002; Rosina, Crisp & Steinbeck 2003). In doing so, these researchers neglect to account for the differences between those in their teenage years and those in their 20s and 30s. For example, teenagers are more likely to live with their parents, and less likely to be involved in a long-term relationship, have children, or be financially independent. Thus, while teenagers may share some similar concerns to young adults, I believe that there is a need to differentiate between these two groups.<sup>3</sup>

Furthermore, research that includes young adults with individuals up to age 50 fails to recognize the different circumstances within this group. According to statistics, most Canadian women have children prior to the age of 40, suggesting that fertility issues are a greater concern to younger women (Bushik & Garner 2008). Furthermore, women with young children will encounter different issues than women with older children, such as childcare (Petersen et al. 2003). Additionally, women in their 20s and 30s may not be established in their relationships and careers, and therefore may also have a distinct experience of illness in this respect. Therefore, it is crucial that research differentiate between young and middle-aged adults in order to situate the illness experience in the social roles and expectations associated with a specific life stage.

Although the definition of ‘young adulthood’ according to either biomedical or psychosocial factors is somewhat arbitrary, social factors may be more pertinent and allow for the recognition of diversity of experience. For example, while individuals in their 20s and 30s may typically seek to establish intimate relationships, careers, and families, many individuals do not accomplish these goals or choose to do so at different times in their lives. Thus, the expectations associated with certain life stages are socially constructed in that they are not

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<sup>3</sup> While Arnett (2000) proposes that a further distinction be made between “emerging adulthood”, ages 18 to 25 years, and young adulthood in contemporary society, I chose to forego making such a distinction in order to capture a broader range of experiences and identify similarities and differences across individuals in their 20s and 30s.



‘natural’ or inevitable for all individuals, nor are some physiological processes such as childbearing and menopause. Exley and Letherby (2001) make a similar point, arguing against the adoption of biomedically defined events as key points in the life course. Accordingly, I have chosen to define young adulthood as pertaining to those individuals between the ages of 19 and 39 because they may share similar concerns and life situations. In particular, it is commonly during these years that individuals seek to establish independence and an individual identity from their family of origin. This may involve: moving away from one’s family of origin, taking responsibility for one’s actions, attending post-secondary education, seeking employment, negotiating intimate relationships, starting a family of one’s own, and becoming financially independent (Grinyer 2007; Lynam 1995). I now turn to the existing literature that has focused on this age group in order to provide a preliminary understanding of young adults’ experiences of illness.

### *2.2.2 Existing Literature on Young Adults with Serious Illness*

Existing research that has highlighted the experiences of young adults has identified a wide variety of issues related to serious illness. The bulk of this research has focused on young adults with cancer, although there are a few existing studies that have included young adults with other illnesses. For example, young adults have been studied with respect to their experiences of illnesses commonly diagnosed in childhood or adolescence such as epilepsy, cystic fibrosis or juvenile arthritis (Badlan 2006; Packham 2004; Raty, Soderfeldt & Larsson 2007) or mental illness such as eating disorders or schizophrenia (Broussard 2005; McCann & Clark 2004). While it is crucial to recognize that young adults with cancer may face different issues than young adults with other illnesses, the existing research provides insight into possible illness-



related issues faced by this population, and contributes to the basis of our understanding of what it is like to be ill during young adulthood. Specific topics addressed in the literature on young adults and serious illness that are foundational for this study are: physical and medical issues, psycho-social issues, and relationship and interpersonal issues.

#### 2.2.2.1 Physical and Medical Issues

While I have included biomedical descriptions of each serious illness affecting the young women in my study in the participant profiles in Chapter Four, in this section, I highlight the physical implications of serious illness as reported in existing research on young adults. Specifically, young adults may experience side effects and physical limitations because of their illness or its treatment. Additionally, certain issues related to medical treatment have also been identified in relation to young adults. It is evident that these physical and medical issues contribute to the psychological and social issues encountered by young adults, and subsequently influence how young adults cope with and adapt to their illness. Such implications of the physical and medical issues that young adults face will be further discussed in the following two sections.

Although young adults with serious illnesses can be affected by a variety of physical changes and limitations, it is useful to recognize some of the common ones, because it is apparent that such physical symptoms can bring about significant changes in young adults' everyday lives and well being. For example, Zebrack (2006) reports that physical changes associated with having cancer can include: "weight changes, hair loss, amputations, placement of catheters, ...scars and alterations in skin coloration and texture" (cited in Grinyer 2007, p.99). Additionally, a case study of a young woman with Hodgkin's lymphoma refers to her experience



of: menopausal symptoms, low energy levels, fatigue, and infertility (Lee 2001). Another study reported that 68% of younger women with breast cancer experienced issues related to body image (Walsh, Manuel & Avis 2005), while additional evidence suggests that changes in physical appearance have an impact on self esteem and psychological functioning (Zebrack, cited in Grinyer, p.99). Further, physical limitations may require that young adults rely on others for tasks that were previously taken-for-granted (Grinyer & Thomas 2001). Thus, substantial changes in everyday life may accompany bodily changes.

Other serious illnesses have similar and unique physical implications to those brought about by many types of cancer. For example, individuals affected by multiple sclerosis may experience: fatigue, loss of strength and mobility, and visual impairment, which may contribute to depression and diminished ability to carry out everyday activities (Zwibel 2009). Epilepsy and medications used in its treatment can also negatively affect young adults' physical well-being, causing tiredness, lack of energy, and difficulty concentrating (Raty et al. 2007). Further, epileptic seizures, or the risk of seizures, can contribute to restrictions in physical activities such as driving and generate feelings of insecurity and anger among others (Ibid). In addition, many serious illnesses cause affected individuals a great deal of pain, which can be physically, emotionally and socially debilitating, as is the case with endometriosis (Markovic, Manderson & Warren 2008). Thus, the signs and symptoms experienced by ill individuals may be disease-specific, but some overlap exists among the physical effects of many serious illnesses.

One prominent concern reported in the literature on young women affected by cancer is infertility (Coyne & Borbasi 2006-7; Dunn & Steginga 2000; Grinyer 2007; Odo & Potter 2009). Specifically, a survey done in the United States with breast cancer survivors shows that 73% of participants under age forty were concerned about possible infertility (Partridge et al. 2004, cited



in Grady 2006, p. 1). Certain cancer treatments can disrupt ovarian function and result in “clinically induced menopause and infertility” (Coyne & Borbasi, p.158). Chemotherapy and bone marrow transplantation in particular are commonly linked with ovarian failure (Grady 2006) and some types of cancer may require the surgical removal of reproductive organs (Baze, Monk & Herzog 2008). For young women with other types of illness, problems with menstruation, fertility and pregnancy may also occur as side effects of illness or its treatment, such as in the case of women with anorexia nervosa (Robinson 2000), schizophrenia (McCann & Clark 2004), or endometriosis (Markovic et al. 2008). These studies demonstrate that serious illness and its treatment have the potential to negatively affect young women’s reproductive capacity and the likelihood of having a healthy pregnancy.

Lynam (1995) reports that the young women in her study were also concerned about the possible effect that cancer treatment could have on unborn children and whether having children was responsible given the possibility of recurrence and death. In some cases, there may be little or no research on the effects of medication on an unborn child or the effects of pregnancy on illness, making pregnancy potentially risky (for example, see Grady 2006 on cancer; O’Keane & Marsh 2007 on depression). In addition, women treated for breast cancer may experience side effects such as fatigue, pain, and decreased interest in sexual contact (Walsh et al. 2005, p.81), which can inhibit sexual relations and the conception of a child, as well as the ability to take care of children. Similar side effects may be experienced by individuals with other types of illness as well (for example, see Forbes, While, Mathes, & Griffiths 2006 for health problems related to MS). Such physical effects of illness have been shown to have a profound impact on individuals’ psychological well being and relationships (Coyne & Borbasi 2006-7; Dunn & Steginga 2000; Lynam 1995), particularly because young women typically take their fertility for granted



(Oakley 1984, cited in Exley & Letherby 2001) and because illness may take away choices about having children (Coyne & Borbasi). Thus, the physical side effects of illness often have far-reaching psycho-social implications and may contribute to disruptions in several realms of life.

In addition to physical side effects, young adults may have medical issues and poor prognoses stemming from delayed diagnoses. According to Albritton and Bleyer (2003), adolescents and young adults may disregard early symptoms of cancer or may not seek health care services because embarrassment or feelings of invincibility, as well as limited access to or inconsistent health care (see also Miedema, Easley & Hamilton 2006). It is also during the teenage and young adult years that parents begin to decrease their role in their children's health (Albritton & Bleyer). Further, health care providers also may not suspect that young adults' symptoms are signs of a serious illness such as cancer, as symptoms may be vague and health care providers often lack experience dealing with young adults or are reluctant to diagnose them with a serious illness like cancer (Albritton & Bleyer; Grinyer 2007; Miedema et al.). Specifically, the unique types of cancer that occur in adolescents and young adults, which are "spontaneous and unrelated to either carcinogens in the environment or family cancer syndromes", may contribute to the illness going unrecognized (Bleyer et al. 2006, p. 591). As such, young adults' illnesses may go undiscovered or undiagnosed, contributing to the progression of illness and worse prognosis. In the case of multiple sclerosis, Kingwell et al. (2010) found that individuals who were young adults at the onset of symptoms had greater delays in being referred to a specialist than older adults, which were associated with higher levels of disability as a result of the disease. Thus, both epidemiological and psychosocial factors play a role in delayed diagnoses for young adults, suggesting that there is a need to generate awareness of possible signs of serious illness in young adults, their families, and health care providers.



In addition to delays in diagnosis, the treatment of young adults and adolescents is further complicated by the lack of appropriate services for this age group. Haase and Phillips (2004) report that adolescents and young adults are rarely treated in appropriate settings, as they are typically placed in either adult or paediatric settings. Thomas (2006) also highlights this issue, referring to this group as occupying a 'grey zone', in that they are not really suited to paediatric care or adult care (cited in Grinyer 2007, p.4). For example, because adult cancer care is often formulated to meet the needs of aging patients, young adults often have unmet needs (National Institute for Health and Clinical Excellence 2005a, cited in Grinyer, p.5). The importance of age-appropriate care is emphasized by Haase and Phillips, who propose that grounding treatment and intervention in the experiences of adolescents and young adults is crucial to treatment adherence and commitment. Therefore, young adults may benefit from age-appropriate care settings, as well as the development of meaningful rapport with health care providers, which may contribute to improved outcomes.

In addition to the lack of appropriate care, research shows that younger individuals may also fail to comply with treatment regimens for a variety of reasons. In a study of young people living with cystic fibrosis, Badlan (2006) indicated that non-compliance with health care regimens resulted from: a lack of time or effort, a busy lifestyle, or the burdensome nature of treatment. Seear's (2009) research on women with endometriosis, many of whom were young adults, also identified several factors as contributing to non-compliance with health care advice, which included: the time-consuming, impractical, and expensive nature of treatment, avoidance of further health problems, and the rejection of medical expertise in favour of subjective experience (see also Markovic et al. 2010). A study on young people with chronic illnesses also reports that many experience problems with adhering to treatment because of emotional and



financial costs, as well as not liking to take medication or wanting treatment to control their lives (Rosina et al. 2003). Thus, non-compliance may result from the nature of available treatments, personal preferences, and individuals' beliefs about their illness. Further, Rosina et al. found a significant negative relationship between poorer psychosocial functioning and treatment adherence in young adults with chronic illness. This finding suggests that access to the appropriate psychosocial services for young adults with chronic illnesses could increase compliance with health care advice and regimens and thus improve health outcomes.

Thus, poor adherence to treatment by young adults, in addition to delays in diagnoses and inappropriate care, may contribute to poorer prognoses. For example, there has been less improvement in survival statistics for the young adult population in comparison to younger and older populations; while cancer mortality rates have decreased for all age groups under 45 years old in the United States since 1975, the least improvement has been in the 20 to 44 year old group (Bleyer 2002). Thus, such medical issues appear to contribute to the potential for young adults to experience their life-threatening or chronic illness as life-limiting and fatal. Grinyer (2007) recommends that the improvement of illness outcomes for young adults will occur through increased awareness of illness, and greater compliance to treatment resulting from collaborative efforts by patients and health care providers to ensure appropriate care. The following section will explore how the physical and medical issues that have been identified in the existing literature cause and intersect with a plethora of psychological and social issues for young adults with serious illnesses.



#### 2.2.2.2 Psychosocial Issues

Along with the physical effects, individuals face significant psychological and social issues as a result of the diagnosis and treatment of a serious illness. Existing research on young adults with illness has identified a wide range of issues that are both unique to this population and shared by individuals of other ages. It is beyond the scope of this review of the literature to address all possible psychological or social issues that arise as a result of illness; but rather, my intent in this section is to highlight and discuss common issues emerging from the literature and how they relate specifically to young adults. This section will also seek to contextualize the physical and medical issues discussed above in order to demonstrate the inter-relatedness of bodily and psychosocial experiences of illness.

A number of studies report that the diagnosis and treatment of serious illness can have negative implications for psychological functioning. In a comparative study of younger and older adults with chronic illness, Scioli et al. (2000) found that younger adults (25 to 40 years old) and individuals with higher levels of chronic illness reported greater psychological distress, and younger adults had lower levels of morale. Research on women with cancer also reveals that younger women with breast and gynaecologic cancer experience greater psychological distress than older women (Politi et al. 2007; Roberts et al. 1991; Vinokur et al. 1990, cited in Roberts et al. 1997). Specifically, young women with cancer may be at risk of anxiety, depression, fear and anger (Coyne & Borbasi 2006-6; Steginga et al. 1998, cited in Dunn & Steginga 2000, p.144), as well as problems with body image (Fobair et al. 2006). Multiple sclerosis has also been found to have a detrimental impact on psychological functioning, with approximately 26% of affected individuals between the ages of 18 and 45 years experiencing depression (Zwibel 2009). Further, depression may have negative implications for individuals' work capacity, relationships, and



adherence to treatment (Ibid). While these studies confirm that many young adults with serious illnesses experience diminished psychological functioning, it is important to explore what factors contribute to poor mental health for this population.

Primarily, anxiety in cancer patients and survivors is commonly related to fear of recurrence and future health problems. Roberts et al. (1997) report that fear of recurrence was the most common problem for the young women who had completed treatment for breast cancer, and was associated with a diminished sense of physical well being. Although fear of recurrence and death is likely common for most individuals affected by cancer and other life-threatening illnesses, Dunn and Steginga (2000) propose that younger women's anxiety arising from the possibility of recurrence may stem from concerns about not seeing their children grow up, rather than fear of death in general. This argument is supported by Coyne & Borbasi (2006-7) who report a similar finding, and Lynam (1995) who found that young adults with cancer were faced with tough decisions about having children, or distress about existing children, because of the possibility of recurrence and death. These studies suggest that young adult women may experience anxiety and existential concerns differently than older individuals; in particular, young adult women may focus on potentially lost opportunities to form a long term partnership, have children, and/or watch their children grow up, as they are more likely to not have children or to have young children in comparison to older adults. Therefore, it is important to recognize that the experience of psychological distress in young adults may be unique from that of individuals of other ages.

In addition to psychological distress, the diagnosis and experience of illness may prompt various emotional states in young adults. A study of young adults with epilepsy reveals that participants experienced a range of positive and negative emotions in regards to their illness; in



particular, young adults discussed positive emotions such as hope and confidence alongside negative emotions such as feelings of anxiety, despair, fear, resignation, indignation, sadness, anger, shame, and self-doubt (Raty et al. 2007). Research on eating disorders also highlights the complex emotions associated with being ill. Broussard (2005) found that young adult women with bulimia felt a great deal of fear because of their illness but were also emotionally attached to it. Rich (2006) describes a similar tension observed in the stories of adolescent females being treated for anorexia, noting that anorexia generated feelings of empowerment and strength, alongside an awareness of its destructiveness. These findings illustrate the profound and complex impact of illness on young people's psychological well-being, as the management of illness in everyday life introduces both positive and negative emotions.

One common psychosocial issue reported in the literature on young adults with serious illnesses is related to independence and, more specifically, the loss of independence that can result from illness. Miedema et al. (2007) report that several of the young adults affected by cancer in their study described feeling as if they had lost their newly gained independence, while Kameny and Bearison (2002) indicate that adolescents and young adults experience pain and anger because the illness experience has taken away their control over being solely responsible for making their own decisions. For example, young adults may need to re-structure their daily routines to accommodate treatment or health care appointments and/or rely on others for assistance in carrying out everyday activities. Such examples of the loss of independence brought about by illness may also be experienced by older adults; however, existing research suggests that the threat to independence imposed by illness is especially hard for young people because their independence has only been recently established (Kyngas et al. 2000) and they are still amidst the process of constructing an adult identity (Odo & Potter 2009). Thus, the loss of



independence may have different implications for young adults in comparison to older adults, and young adults may struggle psychologically and socially with how to maintain their independence in spite of the demands of their illness.

Grinyer and Thomas (2001) posit that the loss of independence incurred by cancer has a distinctive impact during young adulthood in comparison to other life stages because the illness may result in the young adult returning to the care of his/her parents, leaving them with little control over their daily schedules. Adolescents may also resent the loss of independence but they are more likely to still be living with and financially dependent on their parents than young adults. Therefore, having to rely on health care providers, as well as parents' involvement in medical and other decisions, can threaten young adults' recently established independence, and dissolve their sense of control over their lives. This renewed sense of reliance on others, specifically parents, experienced by young adults with cancer is often experienced as a "retrograde step" (Grinyer 2007, p.74), and may affect other aspects of psychological and social well being. In other words, such a loss of independence is experienced by young adults as a failure "to fulfil the 'normal' expectations of the age group" (Ibid, p.72). Thus, the emphasis placed on independence in the existing literature on young adults with cancer speaks to certain expectations associated with young adulthood in Western culture. Specifically, young adults may struggle with the threats to independence brought about by illness because it contributes to feeling as if they have diverged from what is typical of their life stage and that they are not doing what they are 'supposed to'. However, recognition of independence in other areas of life or reciprocity in relationships could potentially alleviate the distress brought about by illness-imposed loss of independence.



The importance of finding balance between self-responsibility for care and reliance on others is highlighted in other research on young adults and chronic illness. For example, a study of young adults with cystic fibrosis found that participants emphasized their desire for control over their lives while also recognizing that they may need help managing their illness (Badlan 2006). Further, resistance to family member's involvement in medical consultations can be difficult for young adults, who may be ill equipped to deal with bad news without support from family members (Grinyer 2002). However, finding a balance may be problematic if parents have difficulties relinquishing control of medical decisions to their young adult 'children' (Morgan & Hubber 2004, cited in Grinyer 2007, p.142). Consequently, young adults and their families may need to find a middle ground where young adults can exercise independence whilst also being supported by their families, particularly because perceived control can positively impact young people's coping and compliance with treatment (Ibid, p.142).

The loss of independence brought about by cancer and other serious illnesses, in the form of reliance on others and the need to structure daily schedules around health care services, compounds the realization that individuals do not have control over their bodies. Research on breast cancer experiences demonstrates how illness, especially a life-threatening one like cancer, disrupts individuals' perceived sense of control: decisions can be made about one's body, but we are also at the mercy of our bodies because of their physicality (Thomas-MacLean 2008). Thus, as a result of illness, individuals may have a changed relationship with their bodies and may not be able to perform activities that they did in the past. Illness may also shake the sense of "invincibility" commonly felt by young adults, particularly because they may have scant experience with ill health and death (CURE 2003; Miedema et al. 2007; Odo & Potter 2009; Roberts et al. 1997). For example, young adults with epilepsy may fear doing things on their own



because of the risk of having a seizure (Raty et al. 2007). Thus, young adults may have to adjust their everyday lives in order to accommodate the limitations introduced by their illness. For instance, individuals with multiple sclerosis may experience the loss of employment because of the physical and psychological effects of their illness (Zwibel 2009).

In addition, young adults may experience this loss of independence and perceived control over their bodies as a threat to their identity and plans for the future. Kidel (1988) suggests that illness undermines individuals' perceived control over the self (cited in Charmaz 1991, p.281); in other words, illness comes as a reminder of the fragility of our being and the lack of control we actually possess in the world. Thus, young adults may find it difficult to integrate illness into their young adult identities because it contradicts their expectations and goals for this life stage. Particularly, plans related to school, work, financial well-being, and relationships may be put on hold or challenged by having a serious illness like cancer (Odo & Potter 2009). As such, young adults may struggle with how to integrate illness into their former identity and manage potential losses resulting from their illness, which may be necessary in order to successfully cope.

One way of managing the loss of independence and perceived control as a result of illness was identified by Kyngas et al. (2000), who indicated that the young people with cancer in their study sought information about their illness and treatment as a means for coping as independently as possible. This notion corresponds to research that suggests that the acquisition of information is a form of coping for individuals of all ages (van der Molen 1999) and part of the process by which newly diagnosed cancer patients gain a sense of control over the situation (McCaughan & McKenna 2007). Other examples of how young adults seek to re-establish control over their lives in spite of illness include: taking action or 'doing' something (Miedema



et al. 2007) and reasserting control in other areas of their lives (Kameny & Bearison 1999, cited in Kameny & Bearison 2002, p.168). Thus, young adults may actively seek ways to maintain or re-establish a sense of independence and control in spite of illness; however these processes may be unique for every individual.

#### 2.2.2.3 Relationship and Interpersonal Issues

The diminished psychological functioning that can result from physical illness has the potential to greatly impact individuals' everyday lives and adjustment to illness. In addition, psychological disruptions can lead to other negative outcomes for young adults, particularly in their relationships and social lives. First of all, the diagnosis of a serious illness can profoundly affect young adults' relationships with their family members, as families are typically a resource for the ill and a major source of social support during times of illness (Pierret 2003; Steinglass 2000). According to Lynam (1995), young adults with cancer do not experience illness as an individual experience, but instead as an experience shared with those who care about them (although Lee (2001) proposes that illness is not a shared experience for young adults in the sense that there are few people who truly understand what it is like to be ill during this time of life; thus, the "shared experience" that Lynam discusses likely stems from the idea that family members' everyday lives are also affected by a young adult's illness). Above all, it is evident in the existing literature that young people view their families as important sources of social support because their relationship is based on caring, rather than complete understanding. Specific issues related to family relationships identified in research on young adults with cancer pertain to: negotiating disclosure of illness, communicating about illness and death, managing



support needs, and wanting to support family members through the illness experience, each of which will be elaborated on in the following paragraphs.

Primarily, it is important to acknowledge that young adults' experiences of serious illness are shaped by past relationships with family, as are their expectations of the role that family members will play in the illness experience (Lynam 1995). In her research, Lynam found that the shared experience of illness for young adults and their families usually generates a new understanding of family relationships; specifically, this author reports that the majority of young adults view their relationships as changing in positive ways, with only one of twelve participants seeing their families as failing to be supportive. In accordance, Kyngas et al. (2000) suggest that the illness experience typically contributes to or affirms close relationships between young people and family members. Therefore, it may be the case that supportive relationships are expected to continue to be supportive during the illness experience, while unsupportive relationships may also continue this way (Miedema et al. 2007). However, it is necessary to recognize that illness will likely introduce distress into the lives of ill individuals and their family members, and place strain on family relationships. In addition, parents may be unable to be supportive of young adults experiencing illness because of practical reasons, such as becoming ill themselves or caring for another ill family member (Coyne & Borbasi 2006-7). Therefore, there are various factors that influence the offer and provision of support by family members, as well as the growth of relationships during the illness experience.

Subsequently, because young adults may not have established a family of intimacy or may be in the early stages of a relationship when diagnosis occurs, young adults often turn to their parents for social support. As discussed previously, young adults may find themselves having to decide whether or not to return to the care of their parents, with some young adults



finding comfort in their return to their parents' home and care, while others may wish to maintain their privacy and discourage attempts by parents to 'fuss' over them (Grinyer 2007, p.58; Hilton et al. 2009; Odo & Potter 2009). In addition to requiring physical care and instrumental support, many young adults become financially reliant on their parents because of their illness. According to Kyngas et al. (2000), financial problems pose substantial difficulties for young people with cancer, many of whom have to borrow money from their parents or a financial institution in order to pay for the costs of living, as well as medications, hospital fees, and sick leave even when public health care services are available. This finding is supported by other research on young people with serious illnesses who were unable to: work, find work after treatment, or make a reasonable wage (Lynam 1995; Odo & Potter; Packham 2004). Furthermore, research demonstrates that financial problems are exacerbated when young adults have dependents (Lynam). Thus, serious illness can place strain on young adults' relationships with their parents, particularly in relation to their need for care and financial support.

According to Hilton et al. (2009), young adults expressed that one of the hardest aspects of the cancer experience was telling family members about their diagnosis because of the pain it caused loved ones. Young adults in this study often felt guilty about causing distress to family members, and some went as far as withholding the diagnosis, certain information, or emotions from family members in order to protect them. Particularly, this study found that males between 18 and 25 years old were more likely to conceal their diagnosis in comparison to male over 25 and young women, as they saw concealing their diagnosis as being in line with their masculine gender identity. Only two women felt it necessary to conceal their illness diagnosis in order to avoid stigmatization because they believed that others perceived the type of cancer by which they were affected (cervical cancer) as being associated with sexual activity and promiscuity



(Ibid). This study therefore identifies specific factors that influence young adults' disclosure of illness and, specifically, that young adults must negotiate the guilt or shame that accompanies introducing stress into their family's lives and the desire to protect them from distress and stigma.

Research has also explored how young adults and their families communicate about a young adult's serious illness. In some cases, family members were viewed as the main source of communication about illness and the resultant fears. A case study of a young woman affected by Hodgkin's lymphoma stated that avoidance behaviour amongst her friends resulted in her family being the only people she could talk to about her illness (Lee 2001). Despite saying this, the young woman also noted that her family never asked about her feelings, specifically with respect to the possibility of dying (Ibid), suggesting that she may have had unfulfilled support needs. Lynam (1995) also discusses the need for families to manage communication about illness and existential concerns, reporting that it was positive for family members to acknowledge the possibility of death while also providing reassurance of survival (p.121). Thus, these studies indicate that avoiding the subject of illness or pretending that death was not a possibility were experienced as negative by young adults who wanted their fears and uncertain situation to be recognized. However, families may struggle with the idea of a child (of any age) dying before his or her parents (Miedema et al. 2007), placing strain on communication between family members.

In addition to negotiating care and support, existing research implies that young adults may also be a source of support to family members during the illness experience. In her study of young adults with cancer, Lynam (1995) found that participants acknowledged their family members' need for support and found ways of supporting them in spite of being ill. A similar situation was reported by Hilton et al. (2009), who indicated that some of the young adults put



forth an upbeat disposition in order to make others feel comfortable and to encourage them not to worry. These findings suggest that young adults can play a central role in helping their families cope with illness; specifically, young adults may offer support to family members or manage their own emotions as a way to influence others. By assuming a supportive role, young adults may be attempting to reciprocate the support their parents have offered them or to restore a sense of independence in their lives.

In addition to managing relationships with members of their family of origin, young adults affected by serious illness may also be required to negotiate relationships with partners and/or children, as it is often during young adulthood that individuals establish or begin to develop intimate relationships and families of intimacy (Baddeley & Singer 2007; Lynam 1995). In a study of younger women with breast cancer, Walsh et al. (2005) found in the quantitative component of their study that communication became problematic with partners as a result of illness because partners were often unsupportive of talking about cancer, death, wills and financial arrangements, the future, and feelings. The qualitative component of the study revealed themes related to increased closeness and intimacy, communication avoidance, separation or termination of a relationship, and problems related to sexuality (Ibid, p. 85). These themes demonstrate that serious illnesses such as breast cancer can introduce various changes into relationships and many couples may experience both positive and negative outcomes. For example, Walsh et al. found that, in spite of 75% of women reporting increased closeness, 35% of women believed their partner was emotionally unavailable and unwilling to discuss illness-related feelings. Thus, the absence of emotional support and communication problems may exist alongside increases in overall caring and connectedness.



Lynam's research also draws attention to the variety of effects that illness can have on relationships for young adults, suggesting that young adults are required to re-evaluate their relationships in light of their illness. In some cases, the illness experience prompted couples to consider how to proceed in relation to marriage or having children, while one young adult stated that illness confirmed the break-up of his/her relationship. Other research also suggests that serious illness can place strain on intimate relationships. For example, one participant in a study of endometriosis reported that her relationship ended soon after her diagnosis and that she remained single since that time because of the implications of her illness (e.g., possible infertility) (Markovic et al. 2008). Furthermore, having a serious illness may negatively affect the establishment of new relationships because the young adult may be viewed as having "baggage" (Odo & Potter 2009) and may risk marginalization (McCann & Clark 2004). Thus, young adults face a great deal of uncertainty with respect to how their illness will affect their established or potential intimate relationships.

Although the need to negotiate relationships with partners is prominent in the existing literature on young adults and illness and particularly young women with breast cancer, more attention has been paid to how younger women manage care and support for their children. As discussed previously, many young women are pre-eminently concerned about how their fertility will be affected by their illness and treatment. Similarly, young adults who had children prior to their diagnosis indicated that a central concern in the illness experience was their children (Coyne & Borbasi 2006-7; Dunn & Steginga 2000; Lynam 1995; Roberts et al. 1997). Specific issues related to children and young adults' experiences of illness that have been identified in existing literature include: shifts in family roles, increased closeness, inability to do as much for and with children, having to negotiate help with child care, the possibility of not being there to



raise them, concerns for children's current and future well being, and the inappropriateness of oncology wards for children (Coyne & Borbasi; Lynam; Roberts et al.; Walsh et al. 2005). In addition, Coyne and Borbasi's study of younger women with breast cancer highlights the need for greater information and support services for women with young children. For example, young mothers may be unsure how to communicate about their illness with children or how to help them cope. Young adults may also experience worries about the possibility of their children developing cancer (Roberts et al.). Therefore, young women with children may experience their illness as particularly problematic because of emotional difficulties with helping children to cope and envisioning the possibility of a future without their mother, as well as physical difficulties with caring for small children.

While there is scant research on how young adults can best assist their children with coping, Coyne and Borbasi (2006-7) recommend that trying to maintain a routine and continue on as normal in spite of breast cancer is helpful for younger women and their children. The idea of maintaining or returning to "normalcy" has also been raised by other researchers, who imply that resuming normal or everyday life is beneficial to the entire family (Kyngas et al. 2000). Miedema et al. (2007) recall that the young adults with cancer in their study felt a strong desire to get back to "normal", even if it was a different kind of "normal" than prior to their diagnosis (p. 48). These studies suggest that even though individual's priorities may be affected by illness, efforts to maintain a sense of "normalcy" can be beneficial for families experiencing illness because disruptions to routines can be detrimental to coping, especially for children. However, further research is needed to explain how families with young children avoid or manage disruptions to everyday life, as well as how individuals resolve possible tensions between continuing on with everyday activities and the existential concerns that accompany illness.



Part of maintaining or returning to “normalcy” involves keeping up relationships with friends and some sort of social life. Existing research shows that friends can be a crucial source of social support during times of illness, and, in particular, that the existence of a large network of family and friends positively affects coping for young adults with cancer (Miedema et al. 2007). However, there is also evidence that young adults experience relations with friends and peers as both positively and negatively. For example, studies by both Lynam (1995) and Miedema et al. report that friends can be positive sources of support for young adults, particularly when they were accepting and comfortable visiting and talking about illness. Friends who were familiar with cancer because of a family member’s experience were viewed as especially supportive by young adults affected by cancer (Lynam). The importance of the support of friends to young adults is likely related to the value placed on friendships during this time of life, as social networks tend to decrease in size during middle age (Hartup & Stevens 1999). Additionally, Lynam suggests that maintaining relationships with friends is a crucial way in which young adults maintain a connection to their life stage, which can provide them with a sense of “normalcy”.

On the other hand, several studies describe how interactions with friends and peers can be experienced negatively for young adults with illness. These studies identify factors that contribute to unsupportive interactions and feelings of isolation. For example, negative interactions often resulted from peers’ lack of understanding or fears of cancer and death (CURE 2003; Lynam 1995). Lee’s (2001) case study of a young woman with Hodgkin’s lymphoma illustrates the tension that can exist between young adults’ desires to talk about illness and the absence of feedback and validation from friends with respect to illness. This young woman stated that there was a great deal of difference between what she wanted to talk about and what



her friends were comfortable with; as a result, she acted in a way that appeased others in order to maintain her friendships. The need to convey a positive outlook to friends is similar to how young adults managed their emotions with family members in order to help them cope (Hilton et al. 2009). Such findings call attention to the tension between young adults' need to communicate about illness and the lack of comfort of friends and family with illness-related issues. Therefore, young adults may choose to internalize concerns about illness and put forth a positive demeanour in order to avoid isolating themselves from their social network, which may in turn be psychologically damaging.

In order to avoid negative interactions, Hilton et al. (2009) reported that some young adults with cancer, particularly those under 25 years of age, are relatively secretive about their cancer diagnosis with friends and colleagues because of fears of being treated differently, excluded, or stigmatized. Although most of the young adults in this study disclosed their cancer to family and close friends, it is crucial to recognize that young adults may wish to keep their illness a secret in order to diminish the impact that it has on their social lives. Despite improved treatments and prognoses for cancer, Flanagan and Holmes (2000) indicate that cancer continues to carry a stigma for individuals affected by various forms of cancer. In particular, certain types of cancer are commonly stigmatized if they can result from failure to take personal responsibility for health, such as lung cancer (Chapple, Ziebland & McPherson 2004), or are associated with sexuality, such as cervical cancer (Baze et al. 2008; Hilton et al. 2009, p.750). Other illnesses including mental illnesses such as depression, schizophrenia and bulimia (Alonso et al. 2008; Broussard 2005; McCann & Clark 2004) and chronic illnesses such as endometriosis and epilepsy (Ablon 2002; Markovic et al. 2008) are also frequently stigmatized and require individuals to decide whether to disclose their illness. Thus, young adults may risk being isolated



from their friends in the event that they are stigmatized upon disclosure of their diagnosis. Given that the physical limitations imposed by illness already hinder young adults' social lives, young adults may wish to avoid any further shrinking of their social network.

#### *2.2.2.4 Summary*

This assessment of the existing literature on young adults who have been affected by life-threatening and chronic illnesses demonstrates the profound impact that being ill can have on young adulthood. While the definition of 'young adult' varies in research, it is evident that there are certain issues that are particularly pertinent to individuals in their 20s and 30s; in addition to the wide range of physical limitations that illness may impose, young adult women appear to be especially concerned with fertility and reproduction. As well, delayed diagnosis, inappropriate care settings, and failure to adhere to treatment recommendations can also affect young adults' experiences and outcomes of illness. Existing research has also explored the variety of psycho-social issues that young adults face because of illness, including the need to negotiate fears of future health problems or recurrence, and the possibility of dying. Such psycho-social issues can have a significant impact on young adults' well being and quality of life, and may alter their relationships and everyday lives. For example, young adults may be required to negotiate relationships with family members, partners, children, and friends with respect to illness, leading to the re-assessment of each relationship. Overall, it is apparent that seriously ill young adults share some of the same concerns as individuals of other ages, although the implications and meanings of these concerns are often different for young adults.



## Chapter Three – Orienting the Research: Methodology, Methods & Research Design

*The study of the process by which meaning is created in illness brings us into the everyday reality of individuals like ourselves, who must deal with the exigent life circumstances created by suffering, disability, difficult loss, and the threat of death... Illness narratives edify us about how life problems are created, controlled, made meaningful (Kleinman 1988, p.xiii).*

### 3.1 Introduction

As Kleinman (1988) eloquently states, illness narratives are more than stories of illness; they provide us with windows to view how illness challenges individuals, and how individuals address those challenges and make meaning of hardship. In this chapter, I orient the reader to qualitative research and the study of illness narratives, in addition to describing my methodological approach and key features of the research process. First, I explain the reasons that I chose to utilize a qualitative approach to study the illness experiences of young adults, drawing from existing literature on illness narratives to support my choice. Next, I elucidate the methodological approach that I utilized, which can be broadly situated in the interpretivist paradigm; specifically, I incorporate features of phenomenological, feminist, and participatory methodologies in order to formulate an approach that values individuals' 'lived experiences' and is sensitive to the impact that gender and power have on everyday life. After describing the methodological approach, I outline the design of the study, including the methods of data generation and participant recruitment and selection. This section is followed by criteria for assessing the credibility of the findings, and considerations regarding ethical issues related to the research. Subsequently, I consider the method of data analysis and the development of research findings.



### 3.2 Qualitative Inquiry and the Study of Illness Narratives

Qualitative research is beneficial to exploring topics about which little is known. Mason (2002) contends that qualitative research can contribute significantly to our understanding of everyday life, experiences, and social processes. One fruitful source of qualitative data lies in individuals' narratives about their experiences of social phenomena, as these stories can yield a more comprehensive understanding of the social world. Richardson (1997) advocates for the inclusion of narratives in sociological research, stating that "narrative is quintessential to the understanding and communication of the sociological" (p. 27). More specifically, narratives allow access to the inner worlds of individuals, and go beyond the classical sociological search for universal, abstract "social forces" (Ibid, p.27). Accordingly, the exploration of individuals' narratives can generate a greater understanding of what it is like to have a certain experience, how the experience affects individuals' lives and identities, and what meanings are attributed to the experience in a specific social context.

Recently in the social sciences, a substantial body of work has emerged with a focus on narratives, and, in particular, narratives of illness. Good (1994) suggests that constructing narratives is useful for individuals who have experienced traumatic events such as serious illness because it involves "the imaginative linking of experiences and events into a meaningful story or plot" (p.118). Illness narratives are thus stories about illness by which individuals try to make sense of their lives and experiences (Thomas-MacLean, 2004). Through the process of telling stories, individuals affected by illness are able to move toward a better understanding of their experiences and the potential changes that have occurred in their self identities and lives as a result of illness. Further, Frank (2000) proposes that storytelling may play a recuperative role for ill individuals who seek to re-claim the voice that illness took from them. Kleinman (1988) also



suggests that having an audience to witness and hear stories of illness can be therapeutic for affected individuals.<sup>4</sup>

Illness narratives also provide an opportunity for storytellers to share their experiences and give others a sense of what it is like to live according to certain “values, meanings, relationships, and commitments” (Frank, 2000, p.361). This statement expresses the idea that illness narratives are an outlet for the generation of understanding; both individuals who tell their stories and those who form the audience learn from the narrative and integrate the understanding that they have gained through telling/receiving the story into their sense of self. Thus, there is often value in the sharing of narratives for both the storyteller and the story’s audience. Foremost, accounts of illness allow others to gain an understanding of what it is like to be ill, which can encourage greater empathy and caring in everyday interactions, as well as in interactions with health care providers (Charon 2006; Frank 1995; Kleinman 1988). Additionally, illness narratives can illuminate the processes by which affected individuals make sense of their illness and how these processes occur in a specific socio-cultural context, thus revealing socio-cultural meanings of illness.

Illness narratives also voice the bodies of individuals’ affected by illness, thereby reflecting our embodied nature. Frank (1995) contends that stories of illness are both about the body and experienced through the body. In saying this, Frank suggests that we would not know illness if not for the interconnection between the mind and body, as illness reminds us that the mind does not exist external to our bodies and we do not control our bodies to the extent that we

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<sup>4</sup> However, not all individuals who experience illness will choose to share their stories and those who do may share them in various forms. For instance, Teucher (2000) proposes that individuals who engaged in writing prior to their illness diagnosis will be particularly likely to generate narratives of their experiences in comparison to others.



often imagine we do. Turner (1984) further articulates this point by saying that “despite the sovereignty we exercise over our bodies we often experience embodiment as alienation... Our bodies are an environment which can become anarchic regardless of our subjective experience of our government of the body” (p.7). This statement highlights the turmoil into which illness thrusts many individuals: the mind’s control over the body is exposed as false by the onset of illness; further, the body’s dysfunction often triggers a separation of the mind and body, almost a re-instatement of Cartesian dualism (Williams 1996, cited in Seale 1998, p. 25). Through illness, it becomes evident that we are able to make decisions about our bodies, but that we are also at our bodies’ mercy (Thomas-MacLean 2008). Thus, the diagnosis of a serious illness may leave individuals feeling betrayed by their bodies, but through telling the story of illness individuals come to understand their bodies and re-discover their sense of embodiment (Frank).

In addition to describing the bodily experience of illness, illness narratives call attention to the disruptions in individuals’ lives brought about by the diagnosis of a serious illness (Bury 1982; Little, Jordens, Paul, Montgomery, & Philipson 1998; McKenzie & Crouch 2004) and their attempts to reconcile aspirations with illness (Riessman 1993). Specifically, narratives demonstrate that serious illness can lead individuals to experience time differently than in the past. Charmaz (1991) describes this shift in the experience of time resulting from illness as “catapult[ing] people into a separate reality – with its own rules, rhythm, and tempo” (p.5). The taken-for-grantedness of life is shattered by the change in everyday routines and not knowing what the future holds. Through the narrativization of illness, the subjectivity of time becomes evident (Richardson 1997) and we come to understand what it means to live in a separate reality. Thus, the examination of illness narratives can illuminate how individuals re-examine and re-frame expectations for their lives and futures in light of illness.



The above paragraphs outline the significance of qualitative inquiry, and particularly the insight offered by the telling and receiving of illness narratives. Through illness narratives, we are able to learn about what it is like to be ill, how illness experiences take on meaning through social interaction, and how the socio-cultural context of illness influences individuals' experiences. Thus, an examination of the stories that people tell about illness can yield insight into multiple levels of the social world, namely the individual, relational, and societal levels. In accordance with my desire to access these multiple levels of the social world, I draw upon a combination of methodological approaches which provide an epistemological and ontological background to the research. Next, I outline key principles of the phenomenological, feminist, and participatory approaches that form the methodology that guided this research.

### **3.3 Interpretivist Research: Creating a Methodological Approach that is Phenomenological, Feminist and Participatory**

Broadly speaking, research falling into the interpretivist paradigm focuses on gaining a better understanding of social phenomena through the exploration of individuals' experiences. An early interpretivist scholar, Dilthey, rejected objectivism and proposed that *Verstehen* was the goal of social research (Willis 2007). Furthermore, he suggested that researchers seek to understand individual experiences through the inclusion of context. This feat involved looking at experiences holistically and avoiding the dissection of individual experiences in order to generalize or develop universal laws or truths (Ibid). Interpretivism is also predicated on a rejection of the possibility of objectivity and universal truths in favour of local and situated knowledge (Ibid). Accordingly, interpretivists hold the following beliefs: i) reality is socially constructed; ii) the purpose of social research is to reflect understanding; iii) data is to be



understood as both contextual and non-universal; and iv) research and practice should be integrated activities that guide one another (Ibid, p.95). Accordingly, interpretivism is suitable for research that aims to explore the experiences of individuals in order to gain a better understanding of a social phenomenon and the meanings attributed to it.

### *3.3.1 Phenomenological Approaches to Social Research*

Within the interpretivist paradigm, one approach to researching subjective experiences of social phenomena is phenomenology. I chose to draw upon phenomenological principles because they correspond to the aim of this research, which is to understand what it is like for young adults to be seriously ill during this time of their life. Phenomenological approaches are theoretically rooted in the philosophical work of Edmund Husserl and Maurice Merleau-Ponty (Good 1994, p.122-3), although they have taken on various forms in contemporary social research (Creswell 1998). In general, phenomenology “offers an account of space, time and the world as we ‘live’ them”, and aims to access descriptions of social phenomena from the perspective of individuals who have experienced them (Merleau-Ponty 1962, p.viii, cited in Good, p.122). Thus, phenomenological approaches to research focus on gaining an understanding of social phenomena via individuals’ “lived experiences”, their experiences of a specific occurrence (van Manen 1990; Creswell), rather than pre-existing ideas about social phenomena. By using such an approach, we are able to learn more about what it is like to have a certain experience, as well as what the “essence” or meaning of that experience is for certain individuals and in certain contexts.



Through the study of a small number of individuals who have experienced a certain social phenomenon, phenomenologists gain a greater understanding of the meanings attributed to their experiences. van Manen (1990) proposes that phenomenology differs from ethnography, symbolic interactionism, and ethnomethodology because phenomenology makes a distinction between appearance and essence (p.32). Stating that “phenomenology is the study of essences” (p.10), van Manen is referring to phenomenologists’ focus on the nature of a phenomenon as it is experienced and made sense of by individuals in a certain socio-cultural context, rather than what can be gathered about that social phenomenon through observational methods. Therefore, the “essence” of a phenomenon is not immediately accessible to individuals who have not lived such an experience (outsiders); however, through the phenomenological study of individuals’ lived experiences using in-depth verbal or written accounts, outsiders can learn about what it is like to experience a certain social phenomenon (its meaning) from the perspectives of those who have lived it. In other words, although one cannot truly know a social phenomenon if such an experience has not been encountered personally, understanding of the social phenomenon can emerge through phenomenological study of subjective experiences. For example, the experience of marginalization may be unknowable for members of a dominant group, but understanding of this social process can be gained through listening and privileging the subjective experiences of marginalized individuals.

The work of Alfred Schutz is particularly important to phenomenological social research because it draws attention to the value of looking at individual experiences within their social contexts, advocating for the examination of “how ordinary members of society constitute the world of everyday life, especially how individuals consciously develop meaning out of social interactions” (Creswell 1998, p.53). Schutz recognizes that individual experiences do not simply



exist on their own, but rather exist within an individual's relationship to and with others. Freund (1990) also speaks to the importance of contextualizing individuals' experiences, claiming that they are embedded in the social structures of a society. Freund states that:

‘External’ social structural factors such as one's position in different systems of hierarchy or various forms of social control can influence the conditions of our existence, how we respond and apprehend these conditions of existence and our sense of embodied self (p. 461, cited in S.J. Williams 2006, p.10).

Thus, both Freund and Schutz indicate the need to examine how individuals' 'sociality' influences their subjective experience and understanding of occurrences in their everyday lives. Good (1994) summarizes this notion, saying that “if experience is inter-subjective and evolves in dialogue with those in the social environment, this dialogue and the structures it mediates are also constitutive of experience” (p.127). As such, the study of lived experiences includes both a focus on individuals' experiences of social phenomena and how they give meaning to their experiences in a specific social context.

As a social scientific approach to research, phenomenology serves as a means by which the embodied nature of individuals can be better understood. A central tenet of phenomenology is the rejection of Cartesian dualism in favour of the concept of “embodiment” or “corporeality”, the acceptance that mind and body are not separate entities (Goldberg 2005; van Manen 1990). As such, phenomenological approaches posit that individuals experience the social world through their bodies. Leder (1992) further emphasizes this point, stating that “we cannot understand the meaning and form of objects without reference to bodily powers through which we engage them – our senses, motility, language, desires” (p.25, cited in Nettleton 2001, p.52). In saying this, Leder elucidates how we interact and engage with the social world through our bodies.



Leder (1990) proposes that our bodies are typically taken-for-granted or ‘absent’ unless they are in pain or suffering, at which time we become acutely aware of them (cited in Nettleton 2001, p.53). With respect to illness experiences, an emphasis on embodiment is particularly relevant because it recognizes that illness is not purely biologically or socially experienced. Kelly and Field (1996) propose that the biological implications of illness are of sociological significance because: “a) they impinge directly on the self; b) they provide signals for identity construction, and; c) they act as limiting factors for the sufferer” (p. 251, cited in Williams 2006, p.11). In saying this, these scholars call attention to grounds on which accounts of illness make evident our embodied nature. Not only do we experience illness through its physical limitations, we experience illness through the implications it has for our individual (re)conception of self, as well as others’ perception of us. McCann and Clark’s (2004) research on schizophrenia provides evidence of this, as individuals who suffer from schizophrenia can experience: changes in bodily appearance and behaviour, the loss of their former sense of self due to these changes and others, and the realization that ‘normal life’ and their envisioned future is now lost. As such, individuals’ bodies are the locations of changes in appearance, self and expectations.

Phenomenological approaches also focus on individuals’ “lived time” or “temporality”, which van Manen (1990) describes as the subjective experience of time as opposed to objective or ‘clock’ time. Furthermore, temporality is subjective because “the past influences how the person lives in the present and this, in turn, affects how the person perceives the future” (Benner & Wrubel 1989, cited in McCann & Clark 2004, p.787). According to Schutz (1971), the everyday world is predicated on having a “common time perspective” that we share with others (cited in Good 1994, p.126); however, such a common time perspective becomes problematic when something disrupts the everyday, taken-for-granted world. Existing research has explored



the meaning of time for individuals affected by life-threatening and chronic illnesses. Charmaz (1991) reveals that “the elusive experience of lived time takes on sharper form when studied from the vantage point of what ill people think, do, and feel about time” (p.167), while Good (1994) indicates that “time [in a shared sense] seems to break down, to lose its ordering power” for ill individuals (p.126). These insights draw attention to how the experience of temporality is changed for ill individuals, who no longer share the “common time perspective” of others nor the taken for granted nature of time. Therefore, phenomenological research is a suitable approach to understand individuals’ “temporal way of being in the world” (van Manen, p.104).

In summary, phenomenological approaches to social research are useful and relevant to this topic for several reasons. First, the focus on individuals’ subjective experiences allows for an exploration of ‘what it is like’ from the point of view of those who have lived a certain experience. Thus, individuals are able to provide details of what they experienced, rather than having to answer specific questions determined by the researcher. Second, the value placed on subjective accounts emphasizes the existence of multiple social realities and negates the possibility of an objective social world that exists external to social actors. As such, I am able to appreciate the stories shared by each participant as unique and equally valuable to my understanding of illness during young adulthood. Third, the emphasis placed on the ‘essence’ or meaning of an experience coincides with my interest in uncovering how meaning is made of certain experiences, and how those meanings are contextual. Therefore, phenomenological approaches recognize that meaning is socially constructed through interactions with others and the social structures and institutions of a society. Fourth, the phenomenological concepts of ‘corporeality’ and ‘temporality’ provide insight into how our experiences are shaped by our embodiment and time perspectives. These concepts are prominent in existing literature on illness



and are particularly useful in illuminating the ‘lived experience’ of illness as opposed to discourses on illness. While additional factors contribute to the suitability of phenomenology to my research approach, these four are significant and correspond to the principles that I draw upon from feminist and participatory methodologies.

### *3.3.2 Feminist Principles for Social Research*

In addition to drawing upon phenomenological assumptions about the social world, I incorporate key principles from feminist approaches to social research. Although there are various forms of feminism, as a whole, feminism can be thought of as “an ethics, a methodology, a more complex way of thinking about and acting upon the conditions of our lives” (Rich 1979, cited in Elliot & Mandell 2001, p.24). In general, feminist perspectives can be characterized by four common characteristics: a desire to understand how social and institutional relations are gendered; a belief that gender is problematic and, along with other social variables, results in inequities in social life; a recognition that gender relations are not “natural”, but rather products of culture and history; and a desire to bring about social change by challenging traditional social arrangements (Elliot & Mandell, p.24). Accordingly, feminist perspectives are critical of existing social relations and seek to bring about greater equality not just among women and men, but also among diverse groups of people. Therefore, feminism should be viewed as “a process of theorizing, rather than as a privileged body of knowledge” (Jackson & Jones 1998, cited in Mandell 2001, p.3).

Epistemologically speaking, many feminists reject the possibility of objectivity and universal truth claims emphasized by positivist-oriented scholars (Mandell 2001). This belief



emerged out of the work of various feminist authors, who critiqued the notion of the universal experience of women put forth by second wave feminists (see for example Hill Collins 1990 or hooks 1981, cited in Mandell, p.4). Instead, many feminists argue in favour of the subjective nature of knowledge in line with interpretivism or constructionism. For example, Haraway (1991) proposes the notion of “situated knowledges” - that all knowledge is produced from a particular social position (cited in Lovell 1996, p.336). This proposition emphasizes that all individuals have unique perspectives of the social world based on the social factors that comprise their identity.

The notion of socially situated knowledge is also evident in the work of Smith (1987), who attacked the discipline of sociology in the 1970s for being male-centered and masculine-focused and driven, rather than objective or neutral as claimed. Smith pointed out that accepted conceptual frameworks in sociology were suspiciously well-suited to the ways that men tend to understand social life, while the everyday experiences of women were absent. This critique drew attention to the inability of sociologists to produce objective knowledge that was independent of their social situation. Smith argued that by making the everyday world problematic feminist researchers construct “a view into the workings of social relations from the standpoint of particular women” (p.182) and reveal the inconsistencies of women’s experiences with supposedly objective theories. Therefore, research that focuses on women and their experiences allows for the generation of greater understanding of the social world from the standpoints of diverse individuals who experience social phenomena via their social position. As well, through research on the diverse perspectives of women, we become more aware of how society is organized according to social factors such as gender and class.



The work of Young (1990) also focuses on the unique perspectives of women in order to expose and challenge the masculine versions of female experience that have previously been passed off as objective or neutral. Specifically, Young explores the significance of the body to women's experiences in her "gynocentric" approach, which aims to revalue and rediscover women's bodily differences, experiences, status, and expression (p.6). Young's work emerges from the realization made by some women that they are attached to their "genderedness" (p.7). In disagreement with claims made by postmodern and poststructuralist feminists that sex is socially constructed alongside gender, some women want the uniqueness of female bodily experiences to be recognized for its value and beauty (see Bordo's (1990) critique of Haraway, cited in Lovell 1996, p.336). Therefore, while Young recognizes that all women experience their bodies and lives differently because of their varied social positions, she demonstrates that women's bodies are unique by presenting phenomenological descriptions of common female bodily experiences, such as pregnancy or being breastfed, in order to highlight the differences in experience between women and men. In doing so, Young exposes the dominant versions of these experiences as masculinist versions that do not reflect women's experiences and serve to oppress women. Feminist critiques of medicalization also accomplish a similar feat, undermining the supposed objectivity of medical and scientific knowledge (see for example, Findlay & Miller 1994; Reissman 2003). Ultimately, such feminist perspectives emphasize the importance of exploring women's bodily experiences in social research in order to understand how the meanings attributed to their experiences differ from the meanings assigned to them by supposedly objective social institutions.

Building on the work of the aforementioned feminists, efforts have been made by contemporary scholars to develop a feminist phenomenology. According to Fisher (2000), both



feminism and phenomenology “share a fundamental commitment to descriptive and experiential analysis” (cited in Chisholm 2008, p.10). Furthermore, drawing upon the work of de Beauvoir (1989) and Young (1990), Goldberg (2005) proposes a feminist phenomenology based on the contention that the lived experiences of women “are uniquely embodied by virtue of gender” and that exploring women’s lived experiences “challenges us to see how these embodied experiences position women in the world of patriarchy” (p.402). This statement furthers the point made by Freund (1990, cited in S.J. Williams 2006, p.10), discussed above in relation to phenomenology, through the acknowledgement that women and men occupy different positions in the social world because of the influence that gender and bodily differences, among other social factors, have on their lived experiences. Therefore, women and men (as well as transgender individuals) have different lived experiences because of their bodily differences, just as all individuals have unique experiences that result from their bodies, social statuses and interactions.

In summary, I draw upon key principles put forth by feminist scholars that correspond to phenomenological assumptions in order to attend to the role of gender in young adults’ experiences of serious illness. Foremost, feminist and phenomenological approaches mutually value and focus on individuals’ lived experiences and what they reveal about the social world. Additionally, both feminism and phenomenology reject the possibility of generating universal or objective versions of social phenomena, and thus favour the notion that knowledge is socially situated. As well, the focus on bodily experiences by feminists such as Young (1990) corresponds to phenomenological approaches, which is evident in the emergence of feminist phenomenology. Through such a blended methodological approach, I explore the experiences of young adult women from their specific standpoints in order to discover their versions of what it is like to be ill during this life stage, and to challenge medical/scientific versions of illness as



masculinist. Overall, the incorporation of feminist principles into a phenomenological approach is valuable because such an approach aids in the recognition of how gender influences bodily experiences of illness and the meanings attributed to them.

### *3.3.3 Participatory Guidelines for Social Research*

In order to address the central principles of phenomenology and feminism, I sought to incorporate aspects of participatory research into my methodological framework. Participatory approaches are orientations to research that seek to gain a greater understanding of the issues that people or communities face through their inclusion in the research process (Minkler & Wallerstein 2003). The specific participatory approach that I draw upon is a visual methodology called photovoice. Photovoice is both a methodology and a method in that it is based on specific epistemological assumptions about the social world and how research should be done, which are grounded in theories of empowerment and inclusion, and it offers guidelines for generating research data (Wang 1999). In this section, I outline key features of participatory methodologies, an overview of visual methodologies, and the guiding principles of the photovoice methodology. I conclude by discussing how a modified version of photovoice is consistent with the phenomenological and feminist methodological underpinnings discussed in the previous sections.

Foremost, I want to acknowledge that there are various participatory approaches to research; however, the common thread in participatory approaches is the rejection of the “colonizing” nature of traditional research (Minkler & Wallerstein 2003) that constructs the researcher as expert and the researched as subject. Instead, participatory research seeks to include participants in the research process as co-researchers who contribute to the direction that



the research takes. Additionally, participatory approaches challenge the possibility of the objective and unbiased researcher (Fals-Borda & Rahman 1991, cited in Castleden, Garvin & Huu-ay-aht First Nation 2008, p.1394). As such, participatory methodologies are based on the premise that researcher neutrality is not possible and that researcher advocacy is acceptable and desirable. The recognition of subjectivity and the inclusion of participants in the research process therefore enable participatory research to focus on the experiences of individuals and communities with the aim of understanding and improving social conditions.

Participatory research also presents opportunities for participants to feel empowered by their involvement in the research process (Israel et al. 1998, cited in Minkler & Wallerstein 2003, p.5). According to Freire's (2002/1973) work on education for critical consciousness, participatory strategies attempt to shift power dynamics to create an egalitarian approach among teacher and learner that can provide opportunities for individuals to take responsibility for their learning (see also, Carlson, Engebretson & Chamberlain 2006 for a discussion of Freire's work and photovoice). For instance, placing value on participants' experience and knowledge can elevate participants' status within the research study and emphasize that they are 'experts' on their lives. Also, freedom to choose the focus of research demonstrates appreciation of participants' knowledge and ability to prioritize the issues they face (Castleden et al. 2008). The involvement of participants in defining the focus of research can also help to: equalize power differences and foster trust among researchers and participants, create a sense of ownership in participants, and prompt social change (Ibid). Thus, involvement of participants in the research process is often beneficial to participants, as well as the overall success of the research.

Visual methodologies are approaches to research that utilize visual data such as photographs or drawings. Some approaches may draw upon visual methods as the main source of



data generation, while others may see images as an additional layer of data that allow researchers to triangulate with other data (Stanczak 2007). While visual data was previously utilized by sociologists and anthropologists because of its perceived objectivity, scholars have come to recognize that visual data is subjective in nature, similar to observational field notes (Prosser & Schwartz 1998); what the image contains depends on the context from which it emerged. Therefore, contemporary visual methodologies typically reflect beliefs that visual data are not reflections of ‘reality’, but instead have meanings that are constructed by the producer of the image, as well as those who view it (Harper 1998). Additionally, contemporary visual methodologies often recognize that visual data will be interpreted differently by individuals of different social backgrounds and in different contexts (Harper 1998). Thus, visual methodologies have moved away from past associations with positivist research to fit within the interpretivist paradigm.

Although there are also several ways of incorporating visual methods into social research, many of these do so in order to make the research process more participatory. Participant-employed photography is one example of a participatory visual method, in that participants have the opportunity to choose the focus of their photographs, which in turn shapes the direction of the research. As well, Davidson (2002) contends that visual data effectively serves as a way to include participants in the interpretation of data in participatory research (cited in Castleden et al. 2008, p.1395). This contention calls attention to the notion that researchers are able to use visual data as a way to elicit interpretations from participants with respect to its content and meaning. Thus, images can be “both a form of data and a conduit for the elicitation of interview data – thereby revealing more and greater details than other methods alone would have generated”



(Shaw 2005, p.239). Thus, visual methodologies can yield richer data and more insightful findings in comparison to other approaches.

The particular visual methodology that I incorporated into my approach is that of photovoice. Photovoice uses participant-employed photography in order to explore individuals' and communities' experiences of social phenomena with the intent of bringing about awareness and social change. This methodology was developed by Wang and Burris (1997) and "uses the immediacy of the visual image to furnish evidence and to promote an effective, participatory means of sharing expertise and knowledge" (p.369). Thus, participants assume the role of educating researchers and others as to what it is like to live under certain social conditions. Photovoice has been successfully used in health promotion research with marginalized populations (see for example, Wang, Burris & Ping 1996, and Carlson et al. 2006) and in research on illness experiences (see for example, Lopez, Eng, Randall-David, & Robinson 2005, and Thompson et al. 2008). Thus, the existing research that has incorporated a photovoice approach demonstrates its usefulness in investigating complex topics about which little is known.

Drawing on principles from feminist theory and critiques of documentary photography, as well as Freire's work on education for critical consciousness (Wang 1999), photovoice as a methodological approach seeks to accomplish a variety of goals. First of all, photovoice builds on feminist theories that advocate for research "by and with women instead of on women in ways that honour women's intelligence and value knowledge grounded in experience" (Ibid, p.185-6). Thus, photovoice draws upon the participatory and feminist principles discussed above, including involving participants in the research process, valuing their experiences and knowledge, and promoting change and advocating for participants (Ibid). Specifically, participants determine the focus of research through taking photographs that reflect their social



realities and sharing the meanings of their photographs and stories about their lives. Thus, the photographic process is central to the inclusion of participants. The photographs and their meanings can then be used to bring about awareness of the issues that participants face and to illustrate to powerful others that improvements in programs or policies are needed. Furthermore, participants' photographs can "interrogate and disrupt the dominant visual terrain" (Poudrier & Thomas-MacLean 2009, p.306) on which young women's experiences of serious illness occur.

Photovoice also emerged out of shifts in visual approaches to social research that sought to overturn the power differences inherent in documentary photography by giving cameras to participants. Wang and Burris (1997) state that giving cameras to marginalized individuals allows them to share their experiences from their point of view, rather than being "passive subjects of other people's intentions and images" (p.371). Thus, participants control what aspects of their lives are photographed and which are not. Further, photovoice methodology draws upon Freire's (1970) work on education for critical consciousness in which he also sought to address power differences (Carlson et al. 2006). As briefly mentioned above, Freire formulated an approach to adult literacy that sought to engage "the learner and the teacher as cocreators of knowledge" and prompt learners to "become aware of their own responsibility for choices that either maintain or change that reality" (cited in Carlson et al., p.837). Thus, learners become empowered through reflection on their current reality and their role in bringing about change. Subsequently, photovoice approaches incorporate photographs and stories "to identify significant community issues, critically reflect on the contributing factors, and identify possible solutions" (Ibid, p.838).

Although specific steps for conducting photovoice research are given, photovoice is flexible and can be adapted to the participants, goals, and research area (Wang 1999; Wang &



Burris 1997). For example, some scholars have blended photovoice with other methodologies (see for example, Lopez et al. 2005) or have modified the research process (see for example, Castleden et al. 2008). Therefore, how photovoice is applied to different topics and groups can vary, but the methodological underpinnings remain the same. As such, I contend that a photovoice approach is suitable for studying young adult women's illness experiences because it offers access to their experiences of being seriously ill from their point of view. Additionally, a photovoice approach can allow for the identification of pertinent issues, raise awareness, and suggest program or policy changes that may benefit this population. In the following section on research design, I outline the way that I applied a photovoice approach to the study of young adults' experiences of illness.

In summary, a photovoice approach can successfully be adopted in social research to achieve participation of the group under study. Based on feminist and empowerment models of research, photovoice offers a more egalitarian approach to research that emphasizes the value of subjective experiences and knowledge. Such an approach can generate rich and detailed data that provides insight into participants' lived experiences (Thompson et al. 2008). Consequently, photovoice corresponds to the phenomenological goal of exploring individuals' direct experiences of a social phenomenon in order to learn more about it. Also, photovoice can reveal discrepancies between dominant versions of a social phenomenon and what individuals actually experience, which ties in with the feminists desire to highlight the experiences of those whose perspectives have previously been neglected. Thus, researchers can learn about what it is like to live under certain social conditions through the words and the eyes of those who live them.



### **3.4 Design of the Research**

In the following sections, I provide an overview of the how the research was conducted and the steps involved in the research process. I first describe the criteria on which participants were selected to participate and methods of recruitment. I also explore issues that arose in relation to recruitment and participation, and how such issues affected who was a part of the study. As well, ethical considerations and issues related to the credibility of the findings are discussed, followed by a description of the analysis of the research data.

#### *3.4.1 Selection and Recruitment of Participants*

In order to gain a better understanding of young adults' experiences of serious illness, I recruited ten participants from around the province of Saskatchewan, using a snowball sampling approach that involved advertisements distributed through the Canadian Cancer Society, the Hope Cancer Centre, AIDS Saskatoon, a brain tumour support group, an ovarian cancer support group, and the University of Saskatchewan online bulletin board, as well as contact with local support organization representatives, and word of mouth. Participants were recruited based on the following characteristics: they were between the ages of 19 and 39 years old, had been diagnosed with a serious illness within the past 2 years, were willing to share personal experiences, take photographs reflective of their experiences of illness, and participate in audio-recorded interviews. Additionally, young adults were able to invite a family member (based on their own definition of family) to participate in the research with them if they wished because I felt that some participants may feel more comfortable participating alongside a family member, and was also interested in learning about how a young adult's illness affected family members.



Firstly, the selection of participants began with the potential participants themselves, as they decided if they thought their illness was considered ‘serious’ and whether to contact me. After being contacted by a potential participant, I sought confirmation that the individual met the above criteria. In addition, once a participant provided information about their diagnosis, I researched the medical description of the illness in order to identify common characteristics and symptoms, as well as possible impacts on affected individuals’ lives. Although the term ‘serious’ may vary in existing research, I chose to define ‘serious illness’ as a diverse group of illnesses that are either life-threatening or chronic (or possibly both) and have significant effects on multiple areas of an individual’s life, such as physical and psychological well-being, relationships, and education/work. In most cases, individuals who expressed interest in being a part of the study and fit the ‘time since diagnosis’ criteria were asked to participate. Ultimately, I wanted potential participants to make the final decision about whether they felt that they had a story to tell about how illness had affected their young adult lives.

It is worth noting that in some cases participants related to me that they appreciated being selected to participate in the study as it validated the severity of their illness, something that may have been lacking in interactions with others. For example, Elizabeth<sup>5</sup> was thankful for my recognition of depression as a serious illness. Nancy also expressed that her participation affirmed the struggle that she was undergoing with the symptoms of her endometriosis, which had been belittled by several health care providers. Enthusiasm was also expressed by participants, including Sandra, Leanne, and Laura, with respect to the opportunity to share their story of their illness and draw attention to illness-related issues. Interestingly enough, some

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<sup>5</sup> As I discuss below, participants were able to choose whether their actual name was used in the research, or a pseudonym was assigned. Six participants chose to use a pseudonym, while four wished for their real name to be used.



participants, such as Nicole and Nancy, believed their illness to be less ‘serious’ or important to talk about than others, typically citing cancer as being more serious, which reflects ideas about the “hierarchy of diseases” (Album & Westin 2008) and the differential attribution of value to certain diseases.

As discussed previously, there is little consensus in the existing literature on illness regarding the definition of ‘young adult’. I chose to define ‘young adult’ as referring to those between 19 to 39 years of age because it captures the time in individuals’ lives when they often experience a number of life changes, such as leaving the family home, obtaining higher education, securing employment, negotiating new relationships, and establishing a partnership and a family of intimacy, among other things. It is also during this life stage that individuals are required to make decisions regarding their futures and enact those decisions. Further, as a young adult myself, I drew on my own experiences and insights into this time of life, as well as those of my peers, in choosing an age range for participants. Despite setting an age range to guide the selection of participants, the definition was somewhat arbitrary and an older individual could have participated if they considered themselves a ‘young adult’.

Overall, 22 individuals inquired about the study, most of whom were willing to participate in the research. Reasons for not being selected to participate and reasons given for declining participation were: diagnosis of illness had occurred several years prior, individual was younger than 19 years of age, individual did not have sufficient time to participate, individual felt that their illness diagnosis was too recent to talk about, and individual did not follow up on initial inquiry for unspecified reason. Although I sought to include both female and male participants in the research, only two males responded to the recruitment advertisements and, of



those two, neither fit the ‘time since diagnosis’ criteria. Thus, all ten participants were young adult females.

One possible explanation for the limited response from young adult males could be related to women’s higher rates of reporting health problems and seeking medical attention (Malterud 2000, cited in Werner & Malterud 2003). Therefore, women might perceive themselves as ill more often than men, meaning that there are more potential female candidates for research on illness.<sup>6</sup> Another possible explanation is that young adult males feel less comfortable talking about illness in general or with a female researcher. For instance, in a study of young adults affected by cancer, young men made up the majority of those participants who were more secretive about their diagnosis with family and friends, often because they viewed talking about illness as inconsistent with their masculine identity; however, this group was primarily made up of male participants under the age of 25, suggesting that age may play a role in men’s willingness to talk about illness (Hilton et al. 2009). Nonetheless, greater response to participation in research on illness and dying by women has been reported elsewhere, perpetuating the notion that women are more expressive than men (e.g., Grinyer 2006).

In addition to seeking individuals of both genders with a variety of illnesses, I hoped to recruit a diverse sample in terms of: the age of participants (within the abovementioned range), race and ethnicity, socio-economic background, geographic location of residence, and family composition, with the goal of accessing a wide range of experiences. I achieved diversity to some extent, recruiting participants ranging in age from 21 to 37 years (average age: 27.4 years). The majority of participants resided in urban centres (both Saskatoon and Regina), while one

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<sup>6</sup> Higher rates of ill health and consultation with health care providers by women may also be related to the greater medicalization of women’s bodies and behaviours (e.g., Findlay & Miller 1994; Riessman 2003).



participant was from a rural area and one resided in a small community near an urban centre. In terms of family composition, the sample was composed of: one participant who was married with two children, two who were married without children, and seven who were dating or single.

Although I did not purposely recruit participants according to socio-economic factors, I hoped that the distribution of recruitment advertisements to a variety of illness-related organizations would yield a varied sample in this respect. As a whole, I received inquiries from individuals with diverse social backgrounds and a wide range of illnesses, however those coming from lower socio-economic backgrounds who expressed interest in participation either did not fit the selection criteria (specifically time since diagnosis) or decided that they did not have sufficient time to complete the study. This sample is composed of seven participants who either had completed an undergraduate university degree or were in the process of doing so and three with graduate level education; none of the participants reported facing severe financial hardships (although illness introduced financial concerns for some). I speculate that time involvement or perceived financial costs of the research could have been a deterrent in recruiting individuals from a lower socio-economic background, and perhaps future research using a similar approach should include an honorarium for participants in order to cover possible costs related to childcare, transportation, communication (telephone or email use), and/or time spent not working. Further, the lack of diversity in participants' socio-economic backgrounds was mirrored by the lack of ethnic diversity in the study. While I did not specifically seek information about ethnicity, none of the participants were visible minorities or indicated such. Reasons for the lack of ethnic diversity in the sample are not known, but my own social background (Caucasian, university-educated) may have influenced potential participants' interest in participating in the study, although this cannot be ascertained.



In addition to the young adult participants, a small number of family members participated in the research in some form. While the opportunity existed for family members to participate in interviews, only one mother of a participant did so; another parent submitted a written description of her feelings regarding her daughter's illness. Other family members were involved in helping participants with taking photographs, and the experiences of family members, especially partners, were frequently discussed by participants during interviews. In some cases, young adults did not seem interested in including their family members, while in other cases it was not feasible because of time constraints and/or geographic location.

### *3.4.2 Steps in the Research Process*

As previously discussed, photovoice approaches to research can take on many forms, and can be a powerful means of learning more about individual and collective experiences of a social phenomenon. I chose to use a modified version of photovoice because the population that I am studying is not a unified group or community residing in the same geographic area, and because individuals joined the study at different points over several months. Thus, similar to what has been reported elsewhere (e.g., Brooks, Poudrier & Thomas-MacLean 2008), the young women began participating in interviews and the photovoice project at different times based on their convenience. Consequently, participants did not come together as a group to discuss their photographs, as is typically the case in community-based photovoice projects (e.g., Carlson et al. 2006; Castleden et al. 2008). Additionally, the research design was flexible and allowed participants to decide how they wished to proceed through the research process; in particular, participants could choose to participate in one or two interviews, depending on their preferences. The six steps involved in the research process were:



- 1) Recruitment and selection of participants (as described above).
- 2) Initial meeting with a participant at time/location convenient for them; project was explained and initial interview performed (if they chose to participate in two interviews) focusing on their lived experience of illness (see Interview Protocol and Guide, Appendix C); information provided regarding the photovoice project (described below).
- 3) Participant completed photographs for the photovoice project over the course of several weeks or months (as deemed necessary).
- 4) Second meeting with participant to perform interview focusing on the photographs that they took and their meanings, as well as follow-up questions on aspects of the illness experience (see Interview Protocol and Guide, Appendix C).
- 5) Participant reviewed transcripts for accuracy and gave consent for interview and photographic data to be included in the study.
- 6) Analysis of data (to be described below); findings were written up and will be disseminated in various forms (dissertation, conference presentations and posters, journal article, report to local support organizations, possible photograph exhibit, etc.).

Overall, I completed 18 interviews with the ten participants. Two chose to participate in one interview, while the remaining eight participants chose to complete two interviews, an initial in-depth interview and a second to discuss their photographs and allow for follow-up questions. Of the two participants who completed one interview, one was interviewed following her completion of the photovoice project, while the other participant only participated in the in-depth interview and did not take any photographs because time constraints resulting from medical appointments and educational/employment commitments prevented her from doing so. The majority of interviews took place at the Qualitative Research Centre (QRC) at the University of



Saskatchewan. The QRC houses an interview room that has been designed to appear more like a living room than an institutional space. The other two interviews took place in participants' living rooms. Interviews lasted between 45 and 120 minutes each, with the average length being approximately 75 minutes. Additionally, nine participants generated a total of 111 photographs, with the number per participant ranging from four to twenty two. One participant did not complete the photovoice project, but I performed an interview with her about her experience of illness.

The interviews involved both phenomenological and photovoice approaches. First of all, phenomenological interviews are “a means of exploring and gathering experiential material” about a social phenomenon (van Manen 1990). Accordingly, this style of interviewing seeks to generate stories about what it is like to have a certain experience from the perspective of those who have lived it, thereby sticking as close as possible to individuals' lived experiences of social phenomena (Ibid). Thus, participants were asked to introduce themselves and then to describe how they learned about their illness. This question typically elicited a long response from the participant that discussed their life prior to diagnosis, the process of being diagnosed, and life since diagnosis. When necessary, I asked participants for specific examples, as well as clarification or elaboration. In some cases, I was required to ask very few other questions because participants talked at length, offering stories about their illness and its impact on their lives and relationships. A minority of participants needed prompting with specific questions that were aimed at generating stories about what it was like to be affected by their specific illness, and the effects that it had on their education/employment, relationships with family, friends, and partners, bodies, and expectations for the future (see Interview Protocol and Guide, Appendix C).



Following the completion of the first interview (or at the initial meeting in one case), participants were given the choice of borrowing a digital camera along with simple instructions or using their own camera to complete the photovoice component of the research. Only one participant chose to borrow the camera available, while the other participants preferred to use digital cameras that they owned. Participants were also given guidelines for completing the photovoice project that included: suggestions about how many photographs to take (10 to 12 each), broad topics that they may wish to focus on (diagnosis, family, everyday activities, social support, relationships, education, employment, etc.), and an explanation of the consent process and the photograph release form that subjects of the photographs were required to sign. At this time, I emphasized that participants could take the photovoice project in any direction that they wished, and take as many or as few photographs as they deemed necessary.

Following the taking of photographs, participants met with me to complete a second interview. The second interview (completed by eight of the participants) focused primarily on the photographs that the participants had taken for the photovoice project. Participants' photographs were transferred to my laptop computer via email or USB memory stick/DVD for us to view together. Participants began the interview by selecting a photograph and talking about the subject, why they had taken it, and what the meaning behind it was. According to Clark-Ibanez (2007), using participant-generated photographs to elicit discussion helps to lessen the awkwardness of interviews because it provides a focus and gives participants something familiar to talk about. Thus, participants were able to lead the interview, deciding what to talk about and when to continue to the next photograph. In some cases, I questioned the participants further in order to elicit more detail regarding photographs. For example, in response to Nancy's explanation of a photograph of the medications that she is required to take, I asked her how long



she had been taking a specific medication. This question elicited a lengthy response about how she must make decisions about this medication on a daily basis, its financial cost, and its implications for her everyday life, which I elaborate on in Chapter Five.

After the photographs had been viewed and explained, participants had the opportunity to talk about anything that had not previously been discussed. I also used this time to ask for elaboration and clarification on the stories shared by participants in the initial interview, or to ask about specific issues if they had not been already broached (e.g., social support, relationship with body in light of illness, education/work, etc). Often, the photovoice project had led participants to reflect on their experiences, which resulted in greater insight being gained in the second interview. For the participant who participated in one longer interview, the first half of the interview was phenomenological in style, exploring her lived experiences of illness, while the second part focused on the photographs that she had taken and the meanings that they held.

### **3.5 Ethical Considerations**

In carrying out this type of research, a number of important ethical issues must be considered. In this section, I highlight specific ethical issues that were addressed prior to initiating the study, as well as throughout the research process. In particular, I discuss issues related to avoiding harm to participants, gaining informed consent for participation, maintaining confidentiality, and ensuring participants had an opportunity to review any data contributed to the study. I also address the nature of the relationship between the researcher and researched with respect to qualitative studies such as this one in order to draw attention to the responsibilities that



qualitative researchers must negotiate. I conclude with some brief comments regarding the need for reflexivity in qualitative research.

One of the basic ethical principles of social research is related to harm, and specifically the imperative that efforts are made to avoid causing harm to research participants (Neuman 2007). This principle is especially important when researching sensitive topics, such as the experience of illness. Although talking about illness is not necessarily distressing, some individuals may find that certain aspects of their illness experience are difficult or upsetting to discuss. Therefore, I took measures to avoid causing unnecessary harm and to ensure that I was prepared in the event that participation brought about distress in a participant. For example, I provided participants with detailed information about the study prior to their agreement to participate in order to ensure that they understood the nature of the research. In one case, an individual who inquired about participating in the study later decided not to because the illness diagnosis was felt to be too recent and upsetting. Thus, learning more about the study helped the participant to see this. Additionally, participants were informed prior to participating that they could withdraw from the study at any point, and that their participation or withdrawal would not affect their access to health care services in anyway.

The use of qualitative methods was another way that I attempted to avoid harm to participants. Specifically, qualitative methods allow for a more flexible research design that allows for data generation to be tailored to the participants in order to minimize distress and anxiety. For example, open-ended questions enable participants to lead discussion and talk about the topics of their choice, thereby allowing participants to avoid sensitive topics if they wished. However, I found that the young adults who participated in this study were incredibly open about their experiences and did not want to gloss over the difficult aspects. In some cases, participants



became emotional, although such moments were temporary and we simply paused for a few moments. In the event that participants became especially distressed, I had previously prepared a list of support organizations that could be contacted regarding counselling services, although none of the participants requested this information.

Although all potential participants initiated contact with me to express interest in the study, written consent was gained from participants prior to each interview. I utilized a graduated consent form that provided participants with details about the study, ethical issues, and contact information. As well, the consent form allowed participants to choose whether their name would be used in the research or if a pseudonym would be assigned, and if they wished to appear in photographs for the study or be de-identified (e.g., faces blurred). Because many of the participants gave written consent twice, the options chosen the second time regarding how they wished to be named and appear in the photographs were taken as their final choice (in the event that they differed). After interviews were transcribed, they were returned to participants for review, at which time any data could be withdrawn or altered. After reviewing the transcripts and photographs, participants were asked to sign a transcript release form acknowledging the use of their data in the study.

Issues of privacy are also important in qualitative research, as researchers should avoid violating participants' privacy to the greatest extent, even in research on personal experiences, and do so only for legitimate reasons. Consequently, I informed participants that they were not obligated to answer any of my questions. Additionally, it is crucial to protect information that participants disclose during research from the public. Thus, it is very important that researchers do not exploit the trust that they have built with participants and consult with participants about the dissemination of personal information along with research findings. As discussed above,



having participants review all data that they contributed to the study allowed them the opportunity to withdraw anything deemed too personal. Personal information such as phone numbers, address, organizational affiliations, and names of health care providers or family members were deleted during the transcription process and kept confidential.

Although issues of privacy are prominent in ethical principles regarding social research, the extent to which participants wish to remain confidential should be negotiated with each participant. In particular, there may be situations in which participants do not want to be completely anonymous, such as can be the case when participants have shared data of a personal nature. Thus, participants may wish to be acknowledged as a participant, or the source or ‘producer’ of certain data because they are proud of their participation. In addition, individuals involved in participatory research may wish to be acknowledged as ‘co-researchers’ through the publication of their names with research data and findings. Therefore, researchers must make decisions throughout the research process with respect to what they feel is the most ethical option for a given situation, especially in participatory research. As discussed above, the consent form that I used allowed participants to decide whether their real name or a pseudonym would be used. Six participants chose to have a pseudonym assigned (Sandra, Laura, Melissa, Nancy, Leanne, and Elizabeth) and four wanted to be identified by their real names (Stacey, Aurelie, Nicole, and Melanie), demonstrating that it is important to consult each participant as to their preference.

In addition to protecting the privacy of participants, the use of photography in social research requires efforts to protect the privacy of those who appear in photographs. In order to do so, I asked each participant to gain consent from any person appearing in one of their photographs through a photograph release form. This form provided details about the study, how



the photographs would be used, contact information for the researchers, and the option to appear or be de-identified in the photographs. Participants gave each person appearing in their photographs one photograph release form to keep and returned one signed copy to myself. Personal information of any person appearing in the photographs was kept confidential.

In addition to taking specific steps to avoid harm and protect the identity of participants in research, qualitative researchers, particularly those using participatory approaches, must consider their relationship with participants on a broader level. According to visual sociologist Gold (1989), the relationship between a researcher and those being researched can be characterized as a covenant, in which both parties enter into a reciprocal, interdependent relationship (cited in Harper 1998). Specifically, qualitative researchers often form relationships with participants that are much more personal than in other types of research, and therefore researchers have a moral responsibility to fulfill obligations to participants and to keep their participants' well being in mind (Schwandt 2007). Thus, participants who come forward to share their experience with a researcher should be met with efforts by the researcher to understand the participants' beliefs, values and worldviews (Gold, cited in Harper, p.30). Researchers should also consider the impact that the dissemination of research findings has on participants and make efforts to avoid harm or embarrassment. Accordingly, I have taken steps to achieve a covenantal relationship with participants by ensuring that I fulfill promises of confidentiality, respect and value their time and stories of illness, and present research findings with their best interests in mind.

Finally, one issue that underlies many of the ethical principles discussed here is that of reflexivity, which is advocated by a variety of researchers including phenomenological and feminist researchers. Harding (1987) suggests that recognizing the role of the researcher and



her/his beliefs increases the objectivity of the research and decreases the objectivism. Accordingly, the inclusion of reflexivity in social research contributes to its ethicality, as researchers acknowledge their own role in the research process. As a young adult researcher interviewing other young adults about their illness experiences, I wanted to ensure that participants were comfortable talking about their experiences and that I was sensitive to their 'ill' statuses. Specifically, I put a great deal of forethought into how my demeanour, appearance, and vocabulary could impact participants' comfort levels and willingness to talk openly about personal experiences. For example, knowing that I was meeting with a participant who had recently had a mastectomy, I did not wear shirts that were revealing or emphasized my 'two-breastedness' in the event that that could be off-putting or upsetting to the participant. Additionally, when analyzing the data, I sought to be conscious of how I could have influenced participants' responses and how any biases or political interests may have entered into discussions with participants or my analysis. Where necessary, I have tried to be explicit in acknowledging in the discussion of the research findings where I have applied my own interpretation or methodological lens to participants' contributions to the study.

### **3.6 Credibility of the Research**

When carrying out and evaluating qualitative research, it is crucial to recognize that it differs from quantitative research in its underlying principles and purpose. According to Bochner (2000), suitable criteria for assessing qualitative research are dependent on our values and paradigmatic approach. As the name suggests, qualitative research is about 'quality'; thus, the aim is to generate research that is of good quality and is meaningful. The means for determining the quality and meaningfulness of qualitative research can vary immensely because they are not



based on quantitative measures of reliability and validity, but instead are subjective and dependent on context. However, I wanted to highlight certain key guidelines by which I sought to ensure the quality of this research.

First and foremost, ensuring the ‘accuracy’ of the data contributes to the reliability and credibility of the research. Seale (1999) advocates for recording participants’ talk verbatim in order to ensure the data reflects their perspectives rather than the researchers (cited in Silverman 2001, p.227). Furthermore, transcribing participants’ words exactly as they were spoken can contribute to the meaning of them, therefore contributing to their ‘accuracy’. Silverman suggests that “failure to transcribe apparently trivial, but often crucial” information diminishes the reliability of the research (p. 230). Accordingly, interviews transcripts include ‘filler’ words such as ‘like’, ‘so’, and ‘um’, and also account for pauses, emphasis, and signs of emotion. Such features of the transcribing process influence the analysis by contributing to the meaning behind participants’ words. For example, pauses call attention to moments of reflection, as well as the emotional nature of parts of interview discussions. In some cases, the quotations from interviews presented in Chapters Four, Five, Six, and Seven have been edited slightly for clarity and brevity when such changes did not appear to affect the overall meaning.

Although qualitative research is not concerned with validity in the same way as quantitative research, Mason (2002) proposes two means of assessing qualitative research for validity. First, the data generation methods can be evaluated for validity, which may include questions about the appropriateness of the methods used with respect to the aims of the research. In relation to this study, I chose to utilize two methods of data generation with the aim of gaining a more complete understanding of the experiences of young adults affected by serious illness. Phenomenological interviews provided an opportunity for participants to share their version of



their illness experiences, highlighting facets that they felt were significant. These interviews also offered opportunities for interaction between the researcher and participants which allowed for the co-construction of meaning, as well as clarification and elaboration by participants. The use of a photovoice approach generated an additional source of data that provided greater insight into what it meant to be ill for the young women. For example, the photographic process prompted participants to reflect on their experiences and realize aspects of the experience that they had not formerly considered. The photographs also elicited further details and stories from participants that, along with the interview data, created a more comprehensive understanding of their experiences.

Mason's (2002) second means for assessing the validity of qualitative research is in respect to the validity of interpretation. Determining the validity of a researcher's interpretations of the data first involves understanding how interpretations were arrived at. In order to do this, researchers must be explicit in how data analysis was performed and on what basis they are making their interpretations. The need for thoroughness and rigour in data analysis is emphasized by Atkinson and Delamont (2007), who suggest that qualitative researchers are often too celebratory of narratives and not systematic enough in their analysis. Thus, providing a clear outline of the steps involved in data analysis is important, and this is found in the following section.

In addition, the recognition of the socio-cultural context in which research data is situated is vital (Atkinson & Delamont 2007). This point is emphatically expressed by Plummer (1995), who states that "while stories are personal, they are shaped by cultural conventions" (cited in Ibid, p.198). As discussed previously in this chapter, the social scientific study of illness narratives has revealed a great deal about how illness is experienced and how meanings



attributed to illness are socially constructed. Therefore, attention to the context in which participants' experiences occur and the context in which their stories are told can yield insight into how the socio-cultural meanings of illness impact participants' experience of illness. In the subsequent chapters, I present the themes emerging from data analysis, alongside a discussion of how the experiences of participants relate to the understandings of illness in the broader context of North American society. I also consider how the research context may have influenced participants' stories of illness and the photographic process.

With respect to the validity of interpretation, it is crucial to recognize the acceptability and necessity of making interpretations about qualitative research data. Specifically, from an interpretivist perspective, making interpretations of data is justified because interpretation is a central part of social life – all interaction requires interpretation by those involved (Schwandt 1998). Additionally, interpretations are essential because research data cannot legitimately stand on its own without some form of analysis. Atkinson and Delamont (2007), among others, warn against being unreflective and uncritical when studying personal narratives lest qualitative research assume a 'talk show' mentality that merely publicizes personal problems and experiences rather than analyzing them. Thus, failure to perform some form of systematic analysis results in a re-presentation of narratives without attention to what they reveal about the social world. In this respect, while I seek to give voice to participants and present an accurate account of their experiences, I also make interpretations of their experiences based on both literal and interpretive readings of the interview transcripts (which are further described in the following section on data analysis). In doing so, I have taken steps to clearly differentiate between my own interpretations and those put forth by participants during the interviews, and to explicate the basis on which my interpretations have been made.



A final issue to consider when evaluating qualitative research lies in the quality and meaningfulness of the presentation of the research findings. van Manen (1997) offers five characteristics on which phenomenological texts can be assessed, which are: lived throughness, evocation, intensification, tone, and epiphany. These five characteristics call attention to the importance of communicating what an experience is like to an audience in a way that they come to recognize or understand that specific experience in a meaningful way. This assessment is somewhat subjective as each individual will encounter a text differently; however, I aim to present the research findings in a way that expresses the details of experience as well as the feelings that accompany them. In doing so, I hope to generate a greater understanding of what it means to be seriously ill during young adulthood in order to improve awareness of the issues that young adults face and make the illness experience less problematic for them. I now turn to a description of the data analysis to show how I arrived at the research findings.

### **3.7 Data Analysis: Coding and Development of Themes**

As I have previously articulated, the aim of this study is to explore the experiential nature of serious illness from the perspective of young adults. In order to do so, I analysed transcripts of the accounts of illness that participants provided during the in-depth interviews. In accordance with phenomenological approaches to social research, the central focus of analysis is on the embodied experience of illness and, specifically, what it is like to be ill as a young adult and the issues that illness introduces. I also examined the photographs generated by participants according to the meanings that they assigned to them in interviews, as well as what the photographs tell us about broader characterizations of illness and young adulthood in our society.



By analysing participants' accounts of illness and their photographs, I seek to connect their individual experiences to broader social structures (Richardson 1997) and socio-cultural ideals regarding the life course. I now outline the specifics of my approach to data analysis.

The analysis of interviews began after the initial meeting or interview took place. This preliminary analysis involved a review of the information provided by participants by listening to the recording of the interview and reading notes made post-interview in order to identify areas in which elaboration or clarification was needed. This review helped to guide the second interview after participants had discussed their photographs. Thus, the second interview, with those participants who took part in more than one interview (n=8), involved questions that were specific to the participant. Additionally, the second interviews allowed me to introduce topics broached by other participants in order to determine if similarities in experience existed among participants. Thus, these interviews provided important directions for my analysis of the data, as they allowed participants to draw attention to relevant aspects of their experiences via their photographs, and for myself to obtain a clearer understanding of the significance of certain issues.

Drawing upon Mason's (2002) guidelines for qualitative data analysis, I identified themes emerging from the data both holistically and cross-sectionally. Holistic data analysis involves looking at individual cases within the data set in order to understand the "particular in context" (Ibid, p.165). Cross-sectional analysis refers to the application of a consistent set of categories to the entire set of data which allows for the identification of similarities and differences (Ibid). By drawing upon both holistic and cross-sectional approaches to data analysis, I sought to generate a comprehensive understanding of each participant's experiences of serious illness, and also common experiences and issues that arose for participants due to illness. The photographs were



also analysed both holistically and cross-sectionally, using both their content and the meanings attributed to them by participants to determine how they were categorized thematically. Such a combination of holistic and cross-sectional analyses was successfully used by Thompson et al. (2008) in their photovoice study that explored experiences of chronic mental illness.

The majority of data analysis occurred once verbatim transcription of the interviews had been completed. Transcription was performed by me and two experienced transcriptionists, following which I compared each transcript against the interview audio-file for accuracy. Then, an initial reading of each transcript was done to generate a preliminary sense of the interview and to identify broad thematic categories. Further readings of the transcripts were then performed to refine the main themes. Once broad themes and sub-themes had been identified, the transcripts were coded using the qualitative software program, *Atlas.ti*. This software aided in coding and organizing the data and allowed for themes to be further refined. As stated above, a holistic analysis of each participant's illness experience yielded themes that are reflective of their subjective experience and its context, which are presented in the participant profiles in Chapter Four. The cross-sectional analysis of the data, which forms the basis of Chapters Five, Six and the first part of Seven, highlights themes that were identified as relevant to the experiences of some or all of the participants.

The analysis process involved reading the data in three different ways: literally, interpretively, and reflexively (Mason 2002). A literal reading of the data involves focusing on the language used by participants to discuss their illness, as well as the content of the interviews and photographs. Such a reading focuses on "what is there" (Ibid, p. 149) and provides an initial understanding of participants' experiences. This type of reading corresponds to phenomenological approaches that advocate for the "bracketing" of the researcher's prior



knowledge and preconceptions about a social phenomenon. According to Creswell (1998), phenomenological approaches to data analysis aim to uncover the “essence” or “the central underlying meaning of the experience” by setting aside all prejudgements and instead “relying on intuition, imagination, and universal structures to obtain a picture of the experience” (Ibid, p.52). Through “bracketing”, I situated my analysis in the words and experiences of participants, rather than in pre-existing beliefs about what it would be like to be affected by a serious illness during young adulthood. While literal readings of qualitative interview data encourage researchers to consider what exactly it is that participants are conveying about their experiences, I believe interpretive readings of such data are also useful and necessary in order to illuminate how subjective experiences are situated in broader socio-cultural contexts.

Further readings of the data allowed for interpretations to be made regarding participants’ experiences, as well as for the recognition of the role that I played in data generation. According to Mason (2002), interpretive readings provide a version of what the researcher thinks the data mean or the insights that have been gained through analysis. Interpretivist approaches contend that making interpretations about other people’s experiences is legitimate because interpretation is a fundamental aspect of social life (see for example, Schwandt 1998). However, I attempt to distinguish, where possible, between my own and participants’ interpretations in order to avoid misrepresenting participants’ understandings of their experiences as conveyed during the interviews. Next, a reflexive reading of the data seeks to reveal the role that I played in and possible influences on data generation and analysis. This type of reading involves a critical analysis of the questions that were asked, my reaction to participants, and my personal biography. For example, a gendered analysis of participants’ experiences emerges from my incorporation of a feminist perspective into my research approach, which in turn may result in



my viewing a certain situation differently from a participant who does not apply feminist thought to their everyday life.

In addition to the interview transcripts and photographs, I referred to documents and other sources of information that participants indicated they had used to learn more about their illness. The information gathered from these additional sources often provided clarification, especially of medical terminology and procedure, as well an insight into what information is available to young adults who are diagnosed with a serious illness. For example, Aurelie gave me a handbook full of invaluable information that is available through the brain tumour support group that she belongs to. Attention was also paid to participants' signs of emotion in the data analysis, which was done by observing emotional states during interviews (e.g., laughter, sniffles, tears), and by noting variations in the dialogue (e.g., pauses, emphasis on certain words or phrases, repetition). These indicators, which were recorded either during or following the interview and in the transcription process, provided supplemental evidence of participants' feelings regarding their experiences. By being attentive to these additional details, as well as employing Mason's three ways of reading qualitative data, I arrived at a more comprehensive understanding and credible analysis of the data than if I had only focused on the text and its literal meaning.

### **3.8 Summary**

In this chapter, I outline my methodological approach to the research, as well as the methods utilized and the design of the research. My aim was to incorporate phenomenological, feminist and participatory principles into my methodological approach in order to access young



adults' lived experience and gain insight into what it is like to be seriously ill during young adulthood. Furthermore, these three methodological approaches place value on subjective experiences because of what they can tell us about the social world and their ability to be a catalyst for social change. In correspondence with such a methodological approach, I incorporated two qualitative methods, in-depth interviews and photovoice. These methods corresponded to the methodological principles adopted from phenomenological, feminist, and participatory approaches and accessed detailed and rich data on young adults' illness experiences. I conclude by highlighting key issues related to the ethics and credibility of qualitative research, and outlined my approach to data analysis. In doing so, I highlight my efforts to be ethically conscious, systematic and reflexive. The following chapter is composed of summary profiles of each the participants' based on the stories that they told during interviews, which highlight the key themes for each participant. Chapters Five, Six, and Seven then build upon these participant profiles by presenting the cross-sectional themes that I identified and situating them in a broader discussion of the existing theory and literature on young adults and serious illness.



## Chapter Four – Participants’ Stories of Illness & Biomedical Information

*Becoming a witness assumes a responsibility for telling what happened. The witness offers testimony to a truth that is generally unrecognized or suppressed. People who tell stories of illness are witnesses, turning illness into moral responsibility (Frank 1995, p.137).*

### 4.1 Introduction

As cited above, Frank (1995) deems storytelling about illness to be done by “witnesses,” from whom we become educated about what it is like to suffer. Further, Frank highlights the moral component that enters such storytelling – to share with others “what really matters” so that people can live fuller and more aware lives (p.145; see also Kleinman 2006). This idea is particularly relevant to the participants of this study, each of whom took the opportunity to share their story of serious illness as a way to raise awareness and possibly help other young adults who might find themselves in a similar situation. In this chapter, I introduce each of the young women in the order that they joined the study through summaries of their stories of illness. The summaries serve as a means to familiarize the reader with the participants and provide background on the context in which illness was experienced. For brevity’s sake, I present a condensed version of each participant’s story, composed of my own words interspersed with quotations from the interviews. I present the words that participants spoke (shown in italics) as accurately as possible, although occasional editing was done for clarity or succinctness.

In addition, I include information on the biomedical aspects of the different illnesses in order to familiarize the reader with the physical component and its potential implications. The intent is to highlight common causes, physical symptoms, and/or treatments associated with each illness, as well as possible illness trajectories. In doing so, I aim to demonstrate the potential physiological and biomedical experiences that these young adults face as a result of illness, as



well as the participants' specific experiences. The information cited is from two sources, *Nursing: Understanding Diseases* (Understanding Diseases 2008) and *Nursing Diagnoses in Psychiatric Nursing* (Townsend 2008), which I consulted because they offer detailed information on each of the illnesses compiled by academics in the field of nursing.

## **4.2 Sandra**

I first met with Sandra and her mother at their house to provide information about the study and to explain the photovoice project. Sandra decided that she would like to participate in an interview after having a chance to take photographs, rather than doing two interviews. Thus, I returned a few weeks later to talk with her and her mother and to view the photographs she had taken. The interview took place in their cozy living room by the fireplace with two dogs and two cats wandering in and out of the room.

I began by asking Sandra about how she discovered that she had multiple sclerosis (MS), to which she answered with a description of the lengthy process involved in arriving at her diagnosis. Sandra recalled that she had been experiencing numbness on the left side of her body; however, at that point, Sandra did not consider that this symptom was the sign of a serious illness, saying that: *The very first thing I thought it was, was a pinched nerve, 'cause I've had pinched nerves before and I thought 'I'm sure that's all it is.' Sandra, along with her mother, continued to recount how Sandra was told by her chiropractor to see a doctor immediately because the numbness was likely more than a sign of a pinched nerve. At the clinic that Thursday evening, Sandra was told by a doctor*



that the numbness she was experiencing could either be a symptom of MS or a brain tumour, and arrangements were made for her to see a neurologist the following Monday.

Enduring the difficulty of waiting all weekend for her appointment, Sandra and her mother met with the neurologist who confirmed that the numbness was of great concern and scheduled medical tests to investigate what was going on. Sandra had an MRI the following week, which prompted Sandra to realize the seriousness of her situation. She said:

*I was surprised that he managed to get me in a week later, or not even a week later, 'cause everyone's like 'You are going to be waiting forever for an MRI.' So I started getting worried, 'Well, if he's pushing it, it's obviously because it's something bad.' But by that point, I had resigned myself to 'It is something bad, we just don't know what level of bad it is.'*

Her words illustrate the way that Sandra interpreted the situation based on her doctors' reactions to her symptoms. After three weeks of waiting for the MRI results, Sandra's mother indicated that they were quite certain that Sandra did not have a brain tumour because they had yet to hear about the MRI results, which was seen as a great relief. Sandra then asked her general practitioner about why she had not heard anything, and was informed that she likely had MS. However, Sandra was told by the neurologist that she met with that, in order to confirm the diagnosis, she would need to experience another episode of MS.

Sandra described how her numbness receded during this process of meeting with health care providers and awaiting test results, and she began to feel better. Not knowing if another episode would occur or when, Sandra continued on with her roles and responsibilities and made plans for a summer vacation. Three days before she had planned to leave with her sister, Sandra awoke to problems with her vision. She recalled:

*I was due to leave the Monday and the Saturday I woke up with this eye thing [not being able to see out of the right eye], and I just knew that that's what it was and I went on the*



*internet and I googled it and sure enough all this stuff is coming up about how this is a classic symptom of MS. It's called optic neuritis.*

After seeing her neurologist, her MS diagnosis was confirmed and she was given a three-day steroid treatment for the optic neuritis, as well as information about medications used to treat MS over the long term.

MS is an autoimmune disease that is a major cause of disability among young adults. It is diagnosed more frequently in women, typically between the ages of 20 and 40, with the average age of onset being 27 years (Understanding Diseases 2008, p.399-401). MS is characterized by episodes of exacerbation and periods of remission, and occurs more commonly among urban populations, upper socioeconomic groups, individuals living in cold, damp climates, and those with a family history, although the exact cause is unknown. As a result of MS, plaques form on the brain and nerve damage occurs, which lead to neurologic dysfunction in various areas of the body. Signs and symptoms may be variable and sporadic, and can include: vision problems, sensory impairment, electrical sensations, bowel and urinary disturbances, dysphagia, fatigue, muscle dysfunction, and poorly articulated or scanning speech. The prognosis for individuals affected by MS varies, with early symptoms often being mild and approximately 70% of those affected experiencing prolonged remission and an active life. However, the disease progression may be rapid in some cases and death can occur within months of onset. Treatment of MS varies with type and symptoms, but may include: interferon and glatiramer medications, other medications, stretching and range-of-motion exercises, frequent rest periods, cooling techniques, and physical therapy, among others. At this time, there is no confirmed cure for MS.

Once given a definitive diagnosis, Sandra began to do research on these medications, along with the help of her father and some friends. Doing research and being involved in the decision-making process were two ways that Sandra coped with her diagnosis. Amidst the



process of making decisions about treatment and applying for financial support for medication costs, Sandra had another MS episode. Again, she experienced eye problems, but this time it was diplopia, or crossing of the eyes resulting in double vision. After receiving another three-day steroid treatment, Sandra began the medication regimen that she had chosen based on her research on other people's experiences with this type of treatment. She recalled how a nurse came to her house to explain to her, her mother and her sister how to inject the medication. Sandra described the two ways by which she could inject herself with the medication: one way *was like an Epi Pen, you know, you just hit a button and it shoots it. But, it's so violent, like it just goes 'pshhh' (explosive noise) and then it's all gone in like two seconds. Whereas if you do it yourself, the needle is smaller than what they give babies, so it's a really small needle.* In saying this, Sandra highlighted how she was required to learn to inject the medication herself.

As a result of the medication, Sandra experienced a variety of side effects and changes to everyday life. As well as frequently experiencing flu-like symptoms after taking her medication, she indicated that the injections result in red bumps at the site that become hot, itchy, and sore. In addition to physical side effects, having to take medication for MS had an effect on Sandra's everyday life because she has had to integrate her medication regimen into her daily routine three times a week. Sandra noted that at first injecting herself was scary, but now has become something that she is used to. She described the injection process:

*It's very ritualized. And to this day, it's not the injection so much as the preparation I hate to have to go, to remember, it has to be refrigerated, to take it out of the fridge, warm it up, I usually put it in my armpit to warm up, go into the bathroom, prepare the site, inject and be done. I just, it's so ridiculous because it takes all of maybe a minute and a half, but it's enough that it, I just feel like annoyed by it. So, other than that, it's pretty easy.*



Despite having developed a ritual for the medication injections, Sandra emphasized that it is a hindrance and reminder of her ill status that she wishes she could avoid. Further, Sandra spoke of how she has to monitor her supply of medication, saying: *It is something that you have to be conscious of because as it starts to run out, I have to re-order it and then I have to make sure I go pick it up and do all that kind of stuff, so yah, it's important to have and to keep in mind.* As these quotations demonstrate, much of Sandra's daily life is now organized around her medication, as she must order, pick up, and take her medication, in addition to dealing with its side effects.

Many of the other issues resulting from the MS diagnosis that Sandra discussed were related to the uncertainty of the illness; specifically, she did not know how quickly MS would progress or what aspects of her physical and mental well-being would be affected. As such, Sandra talked about making her surroundings more comfortable and preparing for future needs. For example, she explained the preparations that had been put in place at her job in the event that the illness progressed, emphasizing how fortunate she had been in this respect:

*I have a great situation at work of, my boss is also my very good friend and so she's been very supportive and always has been, you know, 'Whatever you need, just do it.' Even down to things like when I got diagnosed, it was like 'What can we do to for the "just-in-cases"?' and one of the things that we did was enable remote access connection so I can log in from home into my work computer. So if I was ever in a situation where I felt like I couldn't, I wasn't well enough to be at work, but I could do some work, you know, when I felt up to it, that I could then do it this way. So everybody really jumped on board with that and were really good about setting it up for me.*

This example is one of many illustrations of the crucial support that Sandra received from her family, friends and co-workers, which helped her to cope with the changes brought about by illness and possible changes that could occur in the future.



Although Sandra felt well supported by her family, friends and co-workers, she acknowledged a lack of support from others who were in a similar position as her. Specifically, Sandra had not been able to connect with any other young adults who shared her situation and concerns, suggesting that MS support groups were typically attended by individuals who were suffering a great deal from their illness rather than those in its early stages. While she acknowledged that a lot of information is available on MS and its effects, she clearly articulated a desire to find someone in a similar position; specifically, she believed that it would be valuable to share her experiences and concerns with someone who was at a similar stage in life and the illness trajectory, rather than those who have had the disease for a long time or have already accomplished many of their life goals. For instance, Sandra mentioned concerns related to: dating and when/how to disclose her illness to new acquaintances, and issues associated with becoming pregnant while having MS.

Sandra's story of illness calls attention to challenges arising from chronic illnesses such as MS because of the uncertainty of their effects and progression. In order to cope, Sandra found active ways to manage the lack of certainty, including: researching MS and its treatment, being involved in treatment decisions, planning for issues that could arise in the future, and drawing on family and friends for support. Thus, while she was very much still in the process of making sense of MS, she found ways to feel more in control of her illness. Further, continuing on with her former roles, such as working and going to school, allowed Sandra to maintain a sense of normalcy in her life.



### 4.3 Stacey

When I met Stacey, she was 37 years old and had been diagnosed with breast cancer three times. The first diagnosis occurred a month after her 30<sup>th</sup> birthday, while the most recent diagnosis had occurred when she was 36 years old, approximately one year prior to our first interview.

Breast cancer is a common type of cancer affecting many women and few men. Its cause is unknown, although it is thought to be related to estrogen because of its high incidence in women (Understanding Diseases 2008, p.70-3). Especially at risk for breast cancer are women who: have had endometrial or ovarian cancer, have a family history of breast cancer, have used estrogen therapy or anti-hypertensives, have been exposed to low-level ionizing radiation, eat a high fat diet, are obese, had first child after age 31, have never been pregnant, began menses early or menopause late. Signs and symptoms include: a lump or mass in the breast, a change in symmetry or size of the breast, a change in breast skin appearance or temperature, unusual discharge, a change in the nipple, pain, or edema of the arm. Breast cancer spreads through the lymphatic system and bloodstream, and can move through the heart to the lungs, other breast, chest wall, liver, bone, and brain. Breast cancer is treated with surgery involving either a lumpectomy or mastectomy, and possibly the removal of lymph nodes. Other common treatments include: radiation therapy and chemotherapy, as well as various drug therapies, all of which can have significant side effects.

Stacey communicated that she could no longer separate breast cancer from her identity, as the illness had affected all aspects of her life. Foremost, she discussed the physical changes that had taken place because of surgery and treatment, including an initial modified radical mastectomy, reconstruction, chemically-induced menopause, lymphedema, and later a radical



mastectomy. Each of these physical changes has had an impact on Stacey's everyday activities and the ways that she thinks about her body. These changes have also affected various realms of her life, including: work, relationships, and expectations for the future. She indicated that these changes were difficult to accept and required time for adjustment.

Stacey highlighted the physical changes that she had experienced when she told me about her most recent surgery only a month prior to our initial meeting:

*So basically it was like going back and repeating the mastectomy but this time it's not a modified radical, it's a radical. So they took all of the skin on November 5<sup>th</sup>, they took all of the, well there wasn't a lot of remaining tissue, they took out the implant, they took out, the muscle over top of where the implant was, and did a skin graft from my leg to cover that area, and that I think was the first time that I had to admit that this was really going to change me because the other times you just knew that there was reconstruction and it was going to look fine, you still could wear a bikini if you wanted to, you could still, you know, I mean there was a bunch of scars but who doesn't have a bunch of scars, right? And, but the shape was still gonna be normal. This time, they can never put this [the breast] back together and so this is the first time where I feel really violated.*

Stacey's description communicates her realization after having a radical mastectomy that her body had been altered to the extent that it could no longer be made to look *normal* as it was before. She mentioned on several occasions that these changes made her feel vulnerable. However, when we met again approximately one month later, Stacey felt somewhat better regarding her most recent surgery and had begun to accept the physical changes.

Stacey also discussed changes related to her work and relationships that resulted from her illness. She emphasized the importance that she placed on employment and being successful in her career prior to having breast cancer, stating that:

*It was a really important time in our lives because I had been working for the bank for a long time but I'd just been given, six months earlier, my first management job, so we'd moved... I had my own branch that I was in charge of, you know, at 29 years old that was a really, really big deal - girl, small town, young - and so I was out to prove to the world that this hadn't been a mistake that they'd given me this job, and so when I found this*



*lump and, you know, I didn't really think it was anything but I thought to mention it to the doctor... When it was confirmed that that it was most likely breast cancer, my first thought was 'Oh my god, I don't have time for this. I have a really busy job.' And when they said to me, you know, 'and some people even work part time during chemo', I burst into tears and I was like 'What do you mean I'm going to have to put life on hold for this?' Um, so it was this whole 180 where I was thinking 'Great, I finally accomplished my great big goal and now the rug's being pulled out from underneath me.'*

Stacey emphasized that much of her life and identity at the time was wrapped up in her job, which was threatened by breast cancer. Furthermore, she acknowledged that breast cancer was not something that could be easily fit into her past routines, requiring her to relinquish some of her roles and responsibilities, and shift her priorities.

Ultimately, Stacey framed her multiple cancer diagnoses as signs that she was working too hard and not taking care of herself. She said:

*I tease myself that I needed to get cancer three times because I'm so dense I don't learn [lessons] the first time. And I'm still learning them, like it's a conscious decision everyday to say 'No, you don't need to measure your life by your accomplishments. Today, you need to measure it by feeling good and maybe a nap is what you need, instead of going out into the world and being a grumpy person because you are trying to do things when really you shouldn't be.'*

Stacey reported making various changes to her life as a result of this realization. Foremost, she left her job in favour of one less stressful and time intensive. Further, she and her partner moved to an acreage outside of town where she can rest and take more time for herself. Although having cancer helped her to realize the value of self-care, she said it is something that she easily forgets and has to remind herself of each day.

In addition to trying to enjoy life more, Stacey saw having cancer as a motivating factor to seize new opportunities and realize her dreams. She recalled various opportunities that had arisen in her life specifically because of having breast cancer, such as the chance to provide peer support to other women affected by cancer, to speak publicly about her experiences, and to



participate in fundraisers for cancer research including a snowmobile relay across the province. Opportunities unrelated to breast cancer also presented themselves to Stacey, which were viewed as ways to stop *pressing pause* or putting life on hold for cancer. Most evidently, Stacey and her husband achieved their dream of having their own business, which was not only challenging for her personally but also cemented her relationship with her husband in the absence of children, a cancer-related outcome.

Stacey emphasized that she had received tremendous support from her husband, as well as other members of her social network. She emphasized her husband's calm and practical approach to coping with illness, as well as his patience and support, which have been preeminent in her ability to cope with breast cancer on three different occasions. Above all, Stacey described her experiences as a journey that she and her husband were on together, as both of their lives had been profoundly affected.

Stacey also recognized the support that she had received from family and friends during her illness experience. Specifically, she stated that her sister, brother and sister-in-law provided her with the utmost caring and support. In particular, Stacey appreciated that her sister and sister-in-law would talk openly with her about anything. Further, she valued that her siblings allowed her and her husband to share in the lives of their children. She said:

*My brother and my sister each just have one baby, and my brother and his wife are having another one this upcoming summer, and... these babies are by an extension my babies, you know, because my brother and sister are both very much aware of the fact that [my husband] and I should be going through that process right now too but we might not [due to breast cancer and its treatment], and so both of my siblings have been really amazing about really involving and sharing these little people with us.*

She suggested here that she and her husband had not been able to start their own family because of breast cancer, and this unfulfilled desire was alleviated by being a part of her niece and



nephew's lives. As such, Stacey acknowledged the role of the support offered by her siblings and their selflessness in the coping process. Although Stacey felt that she had received overwhelming support from many individuals in her social network, she recalled a troublesome relationship with her parents, making her siblings' support that much more crucial.

After meeting with Stacey, I felt that her honesty had allowed me to understand how a young woman who had faced breast cancer three times could deal with the ongoing anxiety and uncertainty that cancer had introduced to her life. Overall, Stacey's resiliency was apparent in much of her discussion of the challenges that she faced, whether it was in relation to her aspirations or the losses brought about by illness. Foremost, Stacey emphasized the importance of having a good support network; by communicating with family, friends, and similar others about her experience, she let others into the experience and alleviated some of the metaphorical weight that she was carrying. In response, the majority of those individuals offered the instrumental and emotional support that Stacey needed. Additionally, opportunities to try new things and give back to the cancer community created meaning in her experiences. Although Stacey's illness experience may not have been typical, her story speaks to many of the concerns shared by other young women facing illness.

#### **4.4 Aurelie**

I met Aurelie only a few months after she had completed treatment for a malignant brain tumour that was diagnosed the previous year when she was 24 years old. The diagnosis occurred a few months after experiencing seizures while attending university in Canada. Aurelie told me



that health care providers initially suspected that she had epilepsy which was disproved when an MRI revealed the presence of a brain tumour.

Brain tumours may occur at any age but the incidence in adults is usually between the ages of 40 and 60; in children, brain tumours typically occur prior to age one or between the ages of two and twelve, and are one of the leading causes of death among children (Understanding Diseases 2008, p. 65-70). Signs and symptoms of brain tumours vary depending on the type of tumour, but may include: headache, mental and behavioural changes, decreased motor strength, seizures, altered vital signs, nausea, vomiting, and speech and sensory disturbances.

Confirmation of brain tumours is done using brain, CT or MRI scans, skulls x-rays or cerebral angiography. Treatment can involve surgery to remove the tumour, radiation, and/or chemotherapy, as well as other medications, depending on type of tumour.

Aurelie communicated that she did not immediately realize the life-threatening nature of the brain tumour because of health care providers' initial belief that it was benign. She recalled:

*They [the doctors] said [at first] it was benign so I didn't realize and then [when it was found to be malignant] I had radiation just five minutes every day and I had chemo so... I keep positive, I guess that's the best way, um, but I realize by talking to people, mostly to other patients who were so, so disappointed or so shocked or so, so pessimistic, so that's why I realized it was life-threatening and I could die.*

Here, she indicated that it was after talking with other individuals who lacked such a positive approach that she herself realized the possible consequences of having a brain tumour. Despite making this realization, Aurelie expressed acceptance that she cannot change her diagnosis and emphasized that optimism will help her to cope with illness.

After having radiation therapy and chemotherapy, Aurelie was told by her health care providers that she was now *stable*. Despite the success of her treatment, the illness experience continues for Aurelie. At this time, she has MRI scans every three months and she continues to



take anti-seizure medication which may be a life-long requirement. Additionally, Aurelie experiences lasting physical effects, such as mobility issues and hair loss, which in turn affect other areas of her life. For example, she stated that:

*[The tumour] was on the motor cortex [of the brain] so I can't do what I like or what I used to, maybe sports... because my leg hasn't recovered. So, yeah... I'm tired more quickly than before. Um, I couldn't write, and I can't write like before... but it's only small things, and I take medication every day.*

She indicated that the impact of the brain tumour on her mobility has resulted in her no longer being able to do some of the things that she could before, such as playing sports and dancing. Aurelie also communicated that everyday activities such as writing, opening a door, and climbing stairs, are now difficult to accomplish, which has required her to re-train her body to perform these tasks. Aurelie has had to adjust her former schedule and activities to account for these issues, along with other physical effects of illness and treatment such as fatigue.

Central to the coping process for Aurelie was the support that she received from her family, friends and others affected by brain tumours. Foremost, Aurelie spoke of how her mother came to stay in Canada with her for ten months to care for and support her during treatment. Although only her parents were able to come to Canada during her treatment, Aurelie suggested that being ill has brought all of her family members closer together, which was viewed as a positive outcome of illness. In addition to her family, Aurelie discussed the valuable support that she received from her friends. She recalled examples of how her friends had supported her, including sending flowers, cards, and messages, and coming to visit her. Since returning to university, Aurelie noted that her friends will check up on her if she is absent. These demonstrations of caring from friends help Aurelie to cope with the ongoing implications of her illness and have hope for the future. Further, Aurelie spoke of the many types of support that she



had received from a brain tumour support group that she joined, as the members were a valuable source of information regarding treatment.

In addition to illness having an impact on her physical and emotional well-being, another aspect of Aurelie's life that was affected by illness was her education. At the time that she was diagnosed, Aurelie was living in Canada for the purpose of undertaking a doctoral degree. Because of the brain tumour and required treatment, she took approximately six months off from her program and then spent another three months gradually returning to her studies. Although Aurelie stated that this interruption has not resulted in any significant problems with respect to her education, she indicated that completing her doctorate and obtaining employment were no longer her main priorities. She said: *I'm now in my PhD, but I don't mind if I don't have a good job or whatever because I don't know how long I will live, and it's my priority to just live and be in good health.* Aurelie discussed this shift in priorities several times during the interviews, expressing her newfound recognition of the value of enjoying life and being with family. Furthermore, Aurelie expressed a desire to help other people and considered the possibility of volunteering in or entering the health care field. As such, Aurelie's brain tumour experience had a profound impact on her priorities, as well as how she envisioned her future.

As a whole, Aurelie's story of illness reflects her hope for the future in spite of illness. Speaking openly about the uncertainty introduced by her malignant brain tumour and the possibility of dying, Aurelie reflected on the need to adjust her expectations for her life at various points during the interviews. Despite the uncertainty, Aurelie expressed optimism and a desire to achieve her goals and dreams at the present. She said: *[The illness experience] will never be over but I want to do stuff! Because I miss[ed] one year and a half of my life now and I say 'miss' because I did nothing, or almost nothing... and I really want to get [my life] back, or I*



*know I won't get it back but I just want to enjoy myself!* In saying this, Aurelie captures an idea that many of the participants expressed: the desire to go on with life in spite of the restrictions and unknowns that illness has introduced.

#### **4.5 Laura**

Laura's breast cancer diagnosis occurred just over two years before she first contacted me about participating in the study; however, her story of illness began another two years prior when she was 26 years old. Laura started her story with the initial discovery of a lump in her breast, recounting how her boyfriend (and future husband) was the first to notice the lump. She indicated that she initially dismissed the possibility that a lump existed until a doctor found it during a physical examination a few months later. Being given the choice between a biopsy and removal of the lump or an ultrasound, Laura chose the ultrasound procedure because it seemed less invasive. She recalled this decision by saying:

*I kind of read a little bit and I was like 'Well, the chances of this being anything are so slim and we'll just do this ultrasound thing', which I did every, well first after a month and then after three months and then six months and a year or something like that. I went for two to three ultrasounds and yeah, everything was fine so life went on.*

Here, Laura describes the monitoring of the lump in her breast with ultrasounds over the course of a year, during which time the lump was deemed to be unproblematic. She emphasized that her own thinking about the possibility of having cancer was influenced by her health care providers' belief that *everything was fine*.

Laura continued on to outline the events leading up to her diagnosis:



*So actually about a year and a half went by and I had switched doctors in the meantime and this new doctor doing my physical was like 'Oh, that feels like a, an implant.' I was like 'Oh, this isn't good.' Again, I was like 'Well, I've done everything they told me to do.' And so finally a few months later, in the meantime I'd been fitted for a bra and she's like 'Yeah, everyone has one breast that's bigger than the other' and that was when it like it totally clicked in my brain and I'm like 'Oh my god, like I've never been told that before.' So from there I went back to the doctor and went, you know, 'I think there's really something going on.' and I mean, it was painful and there was all these different things going on and I couldn't ignore it anymore.*

Laura suggested that it took multiple events for her to take seriously the possibility that there was a lump in her breast and that it could be of concern. She called attention to her initial reliance on health care providers to recognize if there was a problem and guide her in the appropriate direction. Eventually, it took a bra fitting for Laura to feel that the signs could no longer be ignored and, despite her young age, it was possible that the lump in her breast was a serious health concern.

Laura frequently referred to how she and others believed that having cancer was not something that was considered given her young age. She spoke of feeling out of place as she sat in the mammogram clinic *with all these, you know, grey-haired people walking by, and I was like 'I'm not supposed to be here.'* Furthermore, the staff at the clinic also reportedly felt this way. When there was a problem with the mammogram requisition form, Laura overheard a nurse say: *If she wasn't so young, we would just do [the mammogram].* She summarized how her age contributed to possible delays in recognizing the seriousness of the lump in her breast, saying that: *Every time, everybody including myself thought that I was too young and just kind of didn't take it seriously enough.* As a result of her experience, Laura felt strongly about raising awareness of breast cancer in young women, which was a motivator for her to participate in this study.



Once it had been confirmed that she had breast cancer through a mammogram and biopsy, Laura underwent aggressive chemotherapy intended to shrink the tumour that had grown to an estimated five centimetres in size. Following chemotherapy, Laura had a mastectomy to remove her breast, and was also administered radiation therapy and hormone therapy. She talked at length about the impact that treatment had on her body, focusing on both the changes in her body's functioning and her appearance. In particular, Laura cited bouts of nausea, sleeping problems, and cramping in her legs as the primary physical side effects of treatment, which she perceived as relatively minor in comparison to others people's experiences and other aspects of her experience. For example, Laura discussed experiencing menopausal symptoms and changes in body composition that she experienced because of the hormone therapy that she is taking for a total of five years. While these changes were viewed as unwelcome, the most significant aspect of being menopausal for Laura was the possibility that her fertility had been threatened by treatment and that she would not be able to have children in the future. As such, this concern is an example of how the effects of treatment extended beyond the physical to also affect Laura's hopes for the future.

Laura also talked about her feelings related to having a mastectomy and its impact on her appearance. She articulated that:

*It's still weird to me to think like I'm missing a breast. It's still not, it still doesn't quite click in my brain, even though I can like stare down and, yeah, it's definitely gone. It's just very surreal, I guess. I don't know. So yeah, it's still kind of dealing with the emotions of having lost a breast.*

Here, she highlighted the disbelief that she continues to feel regarding the removal of her breast, and the confusion that arises from the juxtaposition between the mastectomy site and the other breast. Laura also talked about the changed relationship that she has with her body because of



having breast cancer, specifically recognizing that her remaining breast is now a source of anxiety rather than being a part of her sexuality. In addition to having to negotiate her own feelings related to her mastectomy, Laura talked extensively about having to manage her appearance in interactions with others. Examples she gave related to: wearing a prosthetic when she was around other people and ensuring that her prosthetic was compatible with bras, bathing suits, and other clothing because she worried that she might *freak [some]body out* if her prosthetic was showing or her chest was lopsided, whether or not this would actually be the case. Thus, having a mastectomy affected Laura both in terms of her psychological well-being and socially because she felt the need to manage her appearance for the sake of other people. As such, Laura was in the process of deciding what type of breast reconstruction to have as a way to move beyond the physical effects of illness and match her appearance to her young adult identity.

Laura also discussed the impact that having breast cancer had on other aspects of her life, including her roles and relationships. In relation to her education and employment, Laura described cancer as a setback in that it disrupted her progress in completing a Masters degree and getting her ideal job. Having cancer also required Laura to negotiate her relationship with her partner and their plans for the future. She expressed feelings of guilt because her illness disrupted their plans for the future and caused her partner to worry about her. For example, at the time of her diagnosis, they were planning to get married later that year. In spite of Laura's treatment, they decided that they would not let their wedding date be affected and were married in the autumn of that year. However, Laura's cancer diagnosis did push back plans to buy a house and affected their finances. In addition, they continue to deal with the impact of cancer on plans to have children, as the uncertainty of Laura's fertility has introduced the need to consider adoption.



Laura also discussed the impact of having breast cancer on her relationships with family members. She revealed that communicating with her family about breast cancer was often difficult, particularly with her mother. Laura also experienced a great deal of stress because of the impact that her illness had on her family members. In addition to worrying her parents, she recognized that her sisters would now have to deal with their own at-risk status. Laura indicated that her primary challenge with coping was related to the impact that her breast cancer may have on her family, as opposed to the challenges that she faced. She said: *I worry about me a lot but what I find really hard to deal with is well how this will affect other people... You know, I don't know how to make it better and what if I'm not here to try?* In saying this, Laura expressed her concerns regarding the possibility of dying from breast cancer and how that would affect her family members.

Laura's story draws attention to the ongoing nature of her illness experience. Managing the impact of breast cancer on her body, roles and relationships continues to be necessary, particularly in relation to the desire for breast reconstruction and children. In addition, Laura revealed that she has been plagued by anxiety regarding the possibility of having a recurrence, although she related that her anxieties about recurrence are lessening over time. Part of moving on after cancer has entailed trying to lead a balanced life in which Laura continues to eat healthy and exercise but ensures that she enjoys life and does not worry as much. She summarized this by saying: *In a way I'm more relaxed and I'm like 'Well, you know, I'm just going to enjoy'.*



## 4.6 Melissa

Throughout the interview with Melissa, she talked at length about the health problems that she had experienced from a young age. She recalled her experience of ear infections, bronchitis, and being diagnosed with asthma as a child, and sinus infections as a teenager. Thus, she believed that having immune issues were *kind of a normal part of life*. After a more acute episode of ill health at the age of 14, Melissa underwent tests and it was eventually determined that her gallbladder was not functioning as it should. At the age of 16, Melissa had an operation to remove her gallbladder, which was followed by a period of improved health.

Two and a half years later, Melissa awoke to extreme dizziness, which she initially perceived as a symptom of the flu. After consulting with health care providers, Melissa was diagnosed with an inner ear infection. However, after several weeks of trying to carry on with her roles and responsibilities and no improvement in her symptoms, Melissa returned for medical advice and received medication intended to stabilize the dizziness. Several months later, the dizziness had not subsided, and Melissa obtained eye glasses from an optometrist as a desperate attempt to ameliorate the problem. After this, Melissa recalled: *I had to go into the hospital emergency [room] because I couldn't, I couldn't function anymore. And they thought that there was a possibility of a brain tumour*. This event was followed by an appointment with a neurologist who sent her for an MRI scan to investigate the possibility of a brain tumour. Months of waiting and wondering if she did in fact have a brain tumour culminated in a negative test result and the neurologist telling her to *go back to your family doctor and start again from there*.

After receiving the negative result of the MRI scan, Melissa felt that the neurologist and other health care providers were unsupportive in helping her determine the cause of her



symptoms, although her family doctor continued to send her for other tests. Eventually, health care providers suggested that Melissa's symptoms were psychosomatic or related to depression, which she adamantly disagreed with because of the additional symptoms that had arisen, including fatigue, weight gain, and locked joints. Finally, Melissa recalled that:

*I kind of gave up with medical doctors and I went and seen an alternate health specialist in Alberta and she, um, had said that I had issues with toxicity and so I had so many toxins in my body that this has led up to having this kind of feeling of being too toxic.... Like I could barely move, bend, anything. Um, I was nauseous and tired even if I went for coffee with a friend. Um, if I even went out for 15 minutes just to sit out there with somebody, I would go home and sleep for two hours because that would just wear me out... So anyways when I was on this program with her and, you know, finally after five and six weeks, and finally when I started, like my joints were free again, I was sleeping through the night, the dizziness hadn't completely gone away but it was really manageable, then I was like 'Okay, this is great.' and slowly, but there was one morning I woke up and the dizziness was gone, and finally felt like I was functioning normal again.*

Thus, having not been able to obtain a diagnosis from traditional health care providers, Melissa sought advice from an alternative health specialist who was able to provide relief for her symptoms. Melissa continued on:

*So then I thought that was all great and that was up until [later when] I started having this pain in my foot and I thought 'Oh okay. Oh whatever, it must have just kind....' It wasn't like my ankle, it was in the ball of my foot so I thought 'Okay, maybe I just stepped on something weird.' and, so after it being persistent for a few weeks I went and saw one of the doctors.*

As a result, Melissa returned for medical advice, which once again started a long process of trying to determine the cause of her pain. After over-the-counter medication proved ineffective and x-rays revealed no broken bones, Melissa's symptoms worsened and she soon was unable to walk on her foot. Several weeks later, Melissa underwent a bone scan that again yielded a negative result. During this time, Melissa indicated that she found it difficult to adhere to the program prescribed by the alternative health specialist, and her overall health started to deteriorate.



Having continued with her university classes during this time, Melissa struggled with the physical limitations of the pain that she was experiencing and the side effects of the prescription medication. Further, one health care provider recommended putting her leg in a cast in order to promote healing since a definitive cause of the pain had not been discovered. This led Melissa to acquire a wheelchair to transport herself between classes because using crutches was slow and difficult during the winter months. Although Melissa was able to adapt to her ill health to some extent, her symptoms and resulting limitations had a negative impact on her everyday routine and activities. In addition, medical tests and appointments had yet to yield a diagnosis, and Melissa was again told that there was no medical explanation for her symptoms. However, Melissa continued to seek the advice of numerous health care providers, including acupuncturists, physiotherapists, chiropractors, podiatrists, podorthists, and massage therapists, in order to find ways to alleviate her pain and limitations. Through these health care providers' assistance and her own persistence with stretching, her foot gradually improved and she did her best to avoid further disruptions to her everyday life and plans for this time of her life.

In addition, Melissa began to see a naturopathic doctor who administered bone therapy treatments that contributed to the gradual improvement of the pain. However, Melissa's overall health continued to worsen and she had difficulty eating. She was later hospitalized for kidney and bladder infections. The recurring infections that she experienced led the naturopathic doctor to investigate why her immune system was so weak. After having more tests done, Melissa recalled: *I got that result back first, saying I had hypothyroidism and then I had the results come back from the States saying that I definitely had hypoadrenalism and um, my hormonal levels are really out of whack too.* Thus, after several years of ill health, Melissa finally obtained two diagnoses from a naturopathic doctor.



Adrenal hypofunction, also known as hypoadrenalism, is the result of decreased function of the adrenal gland(s). Primary adrenal hypofunction is relatively uncommon, although it is found in individuals of any age or sex (Understanding Diseases 2008, p.12-4). Signs and symptoms of primary adrenal hypofunction include: anorexia or weight loss, areas lacking pigmentation, darkening or bronzing of skin colour, constant fatigue, craving for salty food, decreased tolerance for stress, nausea, vomiting, irregular pulse, and weakness. Early diagnosis and treatment of adrenal hypofunction result in a good prognosis for affected individuals; however adrenal crisis can occur and may result in coma and death if untreated. Treatment usually involves lifelong corticosteroid replacement and/or oral fludrocortisone to prevent dehydration, hypotension, and other deficiencies.

Melissa was also diagnosed with secondary hypothyroidism, which occurs when there is a low level of serum thyroid hormone resulting from a hypothalamic, pituitary, or thyroid insufficiency (Understanding Diseases, p.308-10). This illness is more prevalent in women than men, and the incidence is rising significantly among people ages 40 to 50 in the United States. The progression of hypothyroidism can lead to life-threatening myxedema coma. Hypothyroidism can be caused by amyloidosis, antithyroid drugs, autoimmune thyroiditis, congenital defects, drugs such as iodides and lithium, endemic iodine deficiency, inflammatory conditions, and pituitary tumours, among other factors. Early stage signs and symptoms include: constipation, fatigue, forgetfulness, sensitivity to cold, unexplained weight gain, whereas later stage signs and symptoms include anorexia and abdominal distention, cardiovascular problems, decreased libido, decreasing mental stability, delayed reaction times, dry, flaky, inelastic skin, dry, sparse hair, hoarseness, infertility, menorrhagia, puffy face, hands, and feet, and droopy upper eyelids. Treatment of hypothyroidism includes gradual thyroid hormone replacement,



while other treatments that support vital signs during a myxedema coma include antibiotics, oxygen and fluid replacement.

Melissa continues to follow a treatment program prescribed by her naturopathic doctor to manage the primary hypoadrenalism and secondary hypothyroidism, as well as recommendations from other alternative health care specialists. In respect to her diagnosis and treatment, Melissa said: *It's still very new diagnosis for me. I'm still learning to deal with it and because we're not doing a conventional, where I just go, you know, and get medications and stuff, or go to surgeries. Um, it's going to be a different type of healing and so it's still not knowing what to expect.* In saying this, Melissa emphasized that she was in the process of determining the implications of illness for her everyday life and continued to face uncertainty regarding what her future will be like. Further, she continued to negotiate her social roles and activities in relation to illness, as the physical implications had necessitated the cessation of certain activities and lowered expectations with respect to certain aspirations. However, Melissa was hopeful for her future since obtaining the two diagnoses and beginning treatment. Her experience highlights the struggle that some individuals, especially women, may face when they experience symptoms that are vague or subjective, such as dizziness, fatigue, and pain. Further, her story of illness raises questions about how health care providers' perceptions of young people may influence their efforts to determine the cause of ill health.

#### **4.7 Nicole**

When I met Nicole, it had been less than one year since she was diagnosed with epilepsy at the age of 20. However, her diagnosis was preceded by other health issues that were



significant to her illness experience. In particular, Nicole had been plagued by migraine headaches throughout her teenage years. Undergoing a variety of medical tests, Nicole was found to have a brain cyst on her left frontal lobe and surgery was performed on the cyst with the hope that this would ameliorate Nicole's migraines and improve her quality of life. Six months after this surgery, Nicole experienced a seizure while at work, which she described by saying: *I had a, um, grand mal epileptic seizure at my work, my old job, and never had anything like that as a kid, never had any kind of shaking symptoms, anything like that. Just out of the blue, [I] had a really bad seizure at work.* Nicole communicated that prior to the seizure she experienced an aura, or flashing lights, as well as nausea, and therefore was aware that something unusual was going on but did not know what was about to happen.

Following the seizure, Nicole was taken by ambulance from her place of work to the hospital. She recalled that she was very confused at the time, not knowing what had happened or why she was being taken to the hospital. Nicole described regaining consciousness at the hospital and seeing her family and her boyfriend:

*I was really upset 'cause I'd just been in hospital six months before for surgery and I was like 'I never want to come back here again' and I was back and I felt like I shouldn't have been, like I was mad. I felt like I shouldn't have been there and it was just confusing 'cause I didn't know quite what was wrong with me and I didn't like having everyone, like my family and stuff be worried about me. It just made me feel really bad so it was strange. I didn't know what I was there for really, and kind of angry that they couldn't tell exactly what it was.*

This quotation illustrates the range of emotions that Nicole experienced being at the hospital. Her confusion regarding what had happened, along with her unhappiness about being back in the hospital and causing her loved ones to worry, resulted in her feeling upset and angry. Although being hospitalized after the seizure was emotional for Nicole, she emphasized that her main concern during this time was for her parents and how worried they were about her.



Epilepsy is a condition affecting the brain that makes it susceptible to recurrent seizures. Approximately 1% to 2% of the population is affected by epilepsy, and the prognosis is good if affected individuals comply with their prescribed treatment (Understanding Diseases 2008, p.199-202). The cause of epilepsy is unknown in many cases, and a variety of factors contribute to its onset in the remaining cases, such as birth trauma, brain tumours, perinatal infection, head injury or trauma, certain infectious diseases, ingestion of toxins, inherited disorders or degenerative diseases, metabolic disorders, and stroke. Signs and symptoms of epileptic seizures vary, but may include: impaired consciousness, amnesia during and after seizure, blinking or rolling of the eyes, falling, and stiffening of affected individual's body with alternating episodes of muscle spasm and relaxation, among others. Treatment commonly involves drug therapy and depends on the underlying cause of the seizures.

Throughout the two interviews, Nicole's comments intimated that she experienced her diagnosis as unexpected and hard to accept. She pointed out that it is atypical to be diagnosed with epilepsy at the age of 20, as she believed that it is more common to be diagnosed in childhood or in the early teenage years when changes are occurring in the brain. Thus, Nicole reported that she lacks similar others with whom she can relate to and knows of only a few other individuals with epilepsy, none of whom were diagnosed as a young adult. Further, Nicole felt that the way that she was given her diagnosis contributed to her difficulty in accepting that she has epilepsy. She recalled:

*That's why I was kind of confused about it too 'cause what [the health care providers] did is, I was in the hospital and they did the EKG on me, and they said 'Yeah, you have irregular brain waves.' and I was like 'Ok, whatever that means.' and they basically said epilepsy and from what I knew, I knew very little about it, but I thought that you had to have a couple seizures and then they would diagnose you, but it seemed just like, they're like 'Yeah, we see something's not right so we'll just', it almost seemed like they kind of just throw it out as a blanket statement and say 'This is what you have, go home.' And*



*they're not, like they think it's caused from the surgery but they're not sure because I was so old when I got it that they don't really know.*

In saying this, Nicole refers to how she questioned her diagnosis to some extent, calling attention to the fact that she had only experienced one seizure. She suggests that the label 'epileptic' was given to her because her health care providers did not know how else to classify her *irregular brain waves*. Further, Nicole felt like her doctors did not take the time to fully explain her diagnosis to her, like she was handed a prescription for anti-seizure medication and then told to go home.

Despite experiencing her diagnosis as problematic, Nicole indicated that she has been able to come to terms with her illness in some ways. For example, she described being able to make sense of what has happened by putting illness in the context of past events. She said:

*It was a shock but it was almost like 'Ok, I knew I took a risk when I, you know, had someone poke in my brain.' So I knew something had to happen so. It was a big shock for them to say you have epilepsy but I kind of thought at the same time like 'Okay, maybe something did happen. Maybe this is why [it happened].'*

In this quotation, Nicole recalls the unexpectedness of her diagnosis and how she understands the cause of the seizure as a possible result of the brain surgery that she had six months before. By identifying a likely cause, Nicole has found a way to make sense of her illness, which helps her to be more accepting of it. She also cites her growing acceptance of illness as being related to increased knowledge of epilepsy and her success in continuing on with many of her previous roles, such as work and school.

Although Nicole has not experienced immense changes in her everyday life, she reported that having epilepsy has had an impact on some aspects of her life. For example, Nicole revealed that her social life has been altered because she is more limited in the activities that she can do with friends. Despite that she continues to go to the bar with her friends, Nicole stated that she



does not feel well when she is there and leaves earlier than in the past. Nicole suggested that this change in her social life was not really a big deal, although she also admitted that she feels limited by her illness because she cannot go out and enjoy herself without worrying about her health.

Another aspect of life that Nicole identified as being affected by her illness was related to her relationships with her parents and her boyfriend. Foremost, Nicole communicated that her loved ones showed greater concern for her than in the past. In regards to her parents, she stated:

*[My parents have] always babied me but my Mom especially, now she's just like 'How are you feeling?' and 'You really got to be careful with work.' and this kind of thing, and I'm just, I'm the kind of person, whatever, I'm going to just push, push, push and keep going and my Mom's like 'Take it easy.' and I think she's more worried about it than I am so. I notice that she's a lot more concerned about [my illness] and always wants to talk to me about it and I just don't want to talk about it.*

In addition, Nicole described how her illness has affected her boyfriend and their relationship:

*It was really hard, like we were together for a year before I had the brain surgery and that was hard on him 'cause he didn't like watching that and then the seizure and he's just kind of like a little, like him and my Mom will gang up on me like, he's like a little mother hen now, he's like 'How are you feeling?' and 'You need to rest.' and he's just very caring, and like he was before but it's a lot more now. He's very worried and very concerned which works out good for me but at the same time like I wonder if [he] feels bad for me. I know, like we've been together for three years now but it's changed a little bit. It changed that he was taking care of me more... I was more the nurturing one and now it's the opposite, he's taking care of me and he makes me sit down and it's just different. It's nice though.*

In both these quotations, Nicole emphasizes that, while she was appreciative of her loved ones' care and support, she also resents the constant focus on her illness and the impact that it has had on her relationships.



In order to illustrate the focus placed on her illness, Nicole gave the example of the heightened concern expressed by her parents, boyfriend and his parents regarding her riding a motorcycle. She described this by saying:

*What bothers me is when I ride my bike I get a lot more questions about how I'm doing and I know they're concerned but sometimes I'm just like 'I just want to go for a ride.' I don't want, you know, they're like 'How are you feeling?', you know, 'Are you scared of anything happening?' and... like we all ride together and it's every time I see them, like 'No, it's [okay].' I just want to go for a ride like I don't, that's why I'm going [because] I don't want to think about it.*

Nicole indicated that riding her motorcycle was no longer the empowering experience it previously had been because it elicited such concerns. Throughout her interviews, Nicole emphasized that others seemed to focus on her illness more so than her and thought that they might perceive her as being limited in what she is able to do. However, she did not agree and stated that she is carrying on with her life and aspirations for the future.

Nicole's story of illness speaks to the idea that coping with and accepting illness is a process. Nicole described experiencing a range of emotions regarding her illness, which were sometimes contradictory. In one sense, she was angry about her epilepsy diagnosis and being different than others her age. But, she also expressed acceptance of her illness and the realization that her situation could be much worse. As well, she discussed the impact of her illness on various aspects of her life, while also downplaying the significance of these changes. However, Nicole indicated that she must continue to deal with the implications of her illness on an ongoing basis because she does not know how it will affect her in the long term.



## 4.8 Leanne

When I met Leanne for the first time, I was truly unprepared for the dramatic story of illness that she was about to share. I began by asking her to tell me a little about herself. Her response included the revelation: *I'm 25. I didn't think I'd live to see my 25<sup>th</sup> birthday, last year, I didn't think I would.* From that point, Leanne proceeded to tell her story of anorexia and the physical, psychological, and social impacts that it had on her. Her account described the chronology of her illness and the rollercoaster that she experienced because of the illness. Throughout her story, she discussed how having anorexia affected her everyday life and priorities and brought about changed meanings of various aspects of life.

Clinically known as anorexia nervosa, this illness affects individuals' sense of body image leading to preoccupation with food, withdrawal from eating, and a distorted view of one's body (Townsend 2008, p.203-4). Anorexia is most prevalent in females between the ages of 12 and 30 years. Signs and symptoms include: morbid fear of obesity, refusal to eat, preoccupation with food, amenorrhea, delayed psychosexual development, compulsive behaviour, extensive exercising, depression and anxiety, and sporadic bingeing and purging. Anorexia can have severe physical implications and can culminate in death if intervention does not occur.

Leanne recalled that she had been overweight as a youth and into young adulthood; through conscious efforts to exercise and eat healthier, she lost a significant amount of weight, which was met with many compliments from friends and acquaintances. Leanne described this time in her life as the happiest that she had ever been. The boost to her self esteem connected to her weight loss, combined with negative social and media influences, contributed to a further desire to lose weight. Leanne stated: *I kept saying like, and I don't know if it was a conscious thing or an unconscious thing, but 'Just five more pounds, just five more pounds then that'll be*



*it*'. Leanne went on to talk about how she progressed from 30 to 60 minutes of exercise a day and eating healthy meals to exercising up to eight hours a day and eating very rarely. Her comments illustrate the onset of anorexia in which efforts to be healthy became an obsessive and problematic part of her life.

Leanne's disordered eating and over-exercising were compounded by a lack of understanding by the health care providers that she came into contact with. An initial consultation with a doctor resulted in the recommendation to eat smaller meals because of high cholesterol (despite the significant amount of weight that she had lost). In response, Leanne internalized this recommendation and further limited her eating. At a consultation a few months later with a specialist in eating disorders, Leanne's mother was told to make her daughter eat as much as possible. Under her mom's supervision, Leanne gained 30 pounds back, which led her to panic and resort to extreme under-eating and over-exercising when she left her mother's home to resume her university education in another city. While away at university, the physical toll of anorexia became evident with the emergence of symptoms such as overall weakness and swelling in her legs. Returning to the eating disorder specialist, Leanne was given diuretics for the swelling that caused drastic weight loss, dropping her to only 76 pounds in five days.

At this point, Leanne's classmates and friends recognized her eating disorder and tried to intervene. Being met with resistance from Leanne, her friends contacted her mother who drove to Leanne's house along with her grandmother. She remembered:

*My grandma and my mom came. And when they came... I could barely walk but like I kind of walked, like furniture walked. And I sat down on the chair and they said 'You're coming home. We're taking you home.' and I fought with them. I said 'No, I'm not going because in two days I'm doing my proposal defence. I'll come home after that.' My mom was like 'How are you going to get there?' I was like 'Well, I'll use a cane, like I'll do anything.' And she said 'No. You can't even get up. You can't do it.' So they had to carry*



*me out of my place, because I was in a basement so there was stairs up, carry me out into the car. And from the car, from my place in here in [this city] they drove me straight to the general [hospital] in [hometown], and that was June 7<sup>th</sup>. I didn't get out of the hospital until August 27<sup>th</sup>. So I was there for about three months. And from there I went to a rehab, I went to a physical rehab centre. So I was there for another half a month. So I didn't get home – I didn't see my house, the inside of my house 'til like September 14<sup>th</sup>.*

This quotation illustrates the physical toll that anorexia had taken, making it difficult for her to walk. Further, Leanne was in denial of her illness and resisted the efforts of her loved ones to help her. However, because of her physical weakness, her mother and grandmother were able to take her to the hospital, which likely saved her life.

Upon admittance to the hospital, a doctor recognized that Leanne's organs were beginning to shut down because of being deprived of essential vitamins and nutrients, and she was admitted to the cardiac unit for medical treatment. Once her body had begun to improve in the cardiac unit, she was moved back to the psychiatric ward for psychological treatment, which she tried to resist but did not have the strength to. During her stay in the psychiatric ward, Leanne experienced further physical problems that contributed to progressive weakening which culminated in her heart stopping. After health care providers attended to her and she had been stabilized, Leanne was then placed back on a medical floor so doctors could take care of her physical needs. A week later, she was having trouble swallowing and breathing and her heart stopped again. Leanne recalled what she had been told about this event:

*I guess while I was in there, I don't remember while I was in there, I said to them, I said 'Let me die.' And as a patient, they have to record your words and what you want. So the doctor went out to the room and he said 'You know, we have to record her last words. These are her last words.' My mom said 'Don't you dare let her die.' And the doctor said 'Thank God you said that, but even if you hadn't, we wouldn't have let her die. She's too young.' So, they worked on me and they took me down to ICU.*

This quotation demonstrates the life-threatening nature of Leanne's illness and how close she came to dying, as well as the communication that took place between Leanne's mother and one



doctor, with both of them wanting to ensure that everything possible was done to save Leanne because of her young age.

Leanne continued on to describe the treatment and recovery process that she underwent in the hospital. During this time, she was highly dependent on others as she was weak and could barely move without assistance. She indicated that many of the health care providers that she encountered were not always compassionate to her situation or attentive to her psychological needs. Further, she believed that some health care providers were unfamiliar with caring for patients of her age or with such a condition. For example, those working in the cardiac unit were used to working with older patients rather than a young woman with heart problems stemming from an eating disorder. Thus, the medical care that Leanne received was not always appropriate and she emphasized that an understanding of eating disorders was greatly lacking among health care providers. Worst of all, Leanne received very little attention from psychiatric professionals until she had been discharged from the hospital and completed rehabilitation.

Leanne also depended on her family for various forms of physical and social support, which affected her relationships with family members. In particular, her mother provided care and emotional support during her recovery, and also dealt with her financial and educational obligations while Leanne was in the hospital (i.e., rent, bills, communicating with Leanne's supervisor). Along with her mother, Leanne's brother and grandparents were important sources of support, visiting her in the hospital often and ensuring that Leanne's needs were being met. In addition, her family members were her main contact with the world outside the hospital. Leanne recalled how her family members would bring messages from her friends, classmates and professors from school, as well as magazines and her laptop once she was strong enough to sit



up. Leanne emphasized that not only did her illness affect her family member's everyday routines, it had a significant emotional impact on them, saying that:

*It was hard on my family. It sucked for them. I've never seen my brother cry, he cried. Never seen my grandpa cry, he cried. It was just terrible. It was so hard on them. And now that I'm doing better, it's still hard sometimes because, not any more but when I first got home, really worried whether I would eat or not, really worried how I was doing. Didn't want me to go back into... old habits. Um, started exercising again. They were really worried that I'd be crazy with that and not doing it healthy and with a couple hours a week, sort of thing, not a day.*

Thus, Leanne's experience of illness has had an ongoing effect on her family relationships because they continue to worry that she might revert to her past problematic behaviour. As a result, Leanne recognized that she must deal with the ongoing implications of having a history of anorexia in her relationships as well as in her own everyday life.

With respect to her recovery, Leanne indicated that it was her who was responsible for taking steps in the process. Specifically, she reported that she chose to eat again because she disliked being dependent on others and wanted to carry on with past roles and relationships. In particular, being away from friends and family was difficult for Leanne, as was falling behind her peers at university. She emphasized that she had encountered a general lack of understanding of anorexia, stating that: *My experience has shown me that people don't know what they're talking about when it comes to eating disorders. They know the physical, they don't know anything else.* As this quotation suggests, Leanne felt that the psychological aspects of anorexia were neglected by health care providers, leaving that part of the recovery process up to her.

Since recovering from her illness, Leanne described various aspects of her life as becoming more balanced. While she still has concerns regarding her appearance and weight, she no longer goes to the extreme lengths that she used to with respect to diet and exercise. Furthermore, she has begun to take a more balanced approach to her education by not allowing it



to consume every day. Her current approach to life was also reflected in the changes that took place in the meaning of different things; specifically, what were previously sources of self doubt, such as food and clothing, are now viewed as enjoyable. I was impressed with Leanne's willingness to discuss the issues related to body image that she struggled with and the physical and psychological hardships resulting from illness, particularly because she almost died. However, her participation in the study was motivated by a desire to educate others in order to improve understanding of and care for individuals suffering from eating disorders.

#### **4.9 Nancy**

I met Nancy shortly before her 22<sup>nd</sup> birthday after receiving an enthusiastic response from her regarding participation in the study. At the time, Nancy was struggling with the symptoms that she was experiencing, as well as her diagnosis of endometriosis. She talked extensively about problematic encounters with health care providers and feeling as if they lacked understanding of her situation. In addition, she highlighted the impact that the symptoms of endometriosis and the side effects of its treatment were having on her life, as it was affecting her busy education and employment schedule. Further, Nancy communicated that her illness was also contributing to difficulties in her relationships with loved ones, which generated feelings of distress and isolation. The following paragraphs describe the process of being diagnosed and treated for endometriosis that Nancy was amidst.

Nancy began by summarizing the symptoms that she was having and her initial attempts to seek medical care. She said:



*Well, I was diagnosed for sure, I guess, in April. But it's been like a struggle since December of like chronic, "oh my God what's happening?" type things. So, I don't know, I had an IUD and that was causing a lot of problems. Like, I wasn't able to do anything and then like having chronic yeast infections for some reason, I mean that never really got solved. And so yeah, just like having to go in and out of – I was in the emergency room twice this year because of the pain being so bad, not knowing what's going on. So, and then, I don't know, finally, like I kept having to see male doctors who would just tell me 'Oh well, I think you're having your period.' 'Yeah, Okay. Thanks. I know what a period feels like and this is not it', you know?*

In this quotation, Nancy describes the pain that she was experiencing and her confusion about what was going on with her body. Later, Nancy also characterized the pain as *kind of like severe menstrual cramps... on [the drug] crack!*, emphasizing the discomfort caused by endometriosis. As a result, Nancy was having difficulties studying for her university final exams and performing her work responsibilities, although she had managed to fulfill the majority of her work and school responsibilities.

In the above quotation, Nancy draws attention to the lack of support that she encountered from health care providers, which had continued throughout the illness experience. She recalled the unhelpful responses of the male emergency room doctors who attended to her and the lack of effort on their part to understand her experiences or be considerate of her suffering. Nancy remembered her frustrations, saying that:

*When they called me back the next day, on Monday, they did the ultrasound and then I had to wait four and a half hours to get the results. And then they said 'Oh, it's nothing. Just go now.' And I like started to cry so hard because I'd been in there for two days. Like 'You guys, why won't you guys even look at me?' No one even looked inside me because they're like 'No, we don't deal with this [gynaecologic health].'*

After failed attempts to obtain a diagnosis or any form of treatment for the pain that she was experiencing from several health care providers, Nancy described how she continued to seek a diagnosis:



*So finally, in like the last week of March of this year, I thought I had a bladder infection just because that's how bad the pain was, and I thought either that or kidney stones, 'cause I was like this is like the worst pain I've ever been in. Um, but then I went to a female doctor and she said 'No, what you're describing to me is endometriosis.'*

Here, she conveys the severity of the pain that she was experiencing and how her persistence in obtaining a diagnosis finally paid off. Nancy indicated that, after receiving a tentative diagnosis from this female gynaecologist, she was prescribed birth control pills to treat the endometriosis.

Endometriosis occurs when endometrial tissue forms outside the lining of the uterus. Its cause is unknown, but family susceptibility or recent hysterotomy may be contributing factors (Understanding Diseases 2008, p.195-6). The ectopic endometrial tissue can appear anywhere in the body but usually remains in the pelvic area where it bleeds during menstruation, causing inflammation in surrounding tissues. As a result, fibrosis may occur, which can lead to adhesions that in turn cause pain and infertility. Endometriosis is most common in women between ages 30 and 40, particularly those who have not bore children, and is relatively uncommon prior to age 20. Signs and symptoms of endometriosis may include: pain in the pelvic region the week prior to and during menses, profuse bleeding, abdominal cramps, nausea, and vomiting, among others. Treatment typically involves the use of androgens, progestins and hormonal contraceptives, and other hormone treatment, laparoscopy, and surgery, including total abdominal hysterectomy or bilateral salpingo-oophorectomy.

Nancy reported feeling very strongly against using birth control pills as a form of treatment for the endometriosis, but lacked information on other options. She recalled the conversation between her and the gynaecologist on this subject:

*She was the one who put me on to birth control, and who was like 'You have this. See you in three months.' ...I'm not excited 'cause the reason I had an IUD in the first place was because that was the only non-hormonal birth control that's available other than, you know, maybe hoping... This is like what I didn't want... and then I was in like a bitchy*



*mood because, you know, right in the middle of finals and like they're putting me on hormones- 'This'll go well!', you know? So, I don't know, she said, 'Well, your life is pretty miserable as it is. You might as well try this.' I was like 'Ah...' ...They weren't talking about [other possibilities], and like I think I'm going to try maybe something else and see what's available out there. Like I've been recommended to a few other people, like naturopaths and other things like that. And yeah, I'm so sick of being on hormones because I've been on them before and like I go crazy! That's why I don't want to be on this.*

At the time she met with the gynaecologist, Nancy felt largely powerless to cope with her illness and its symptoms because she was also experiencing side effects of the birth control pill, including mood swings and excessive hunger. Since then, she has begun to investigate alternative ways to treat endometriosis, while also taking the birth control pills that have been largely ineffective.

Acknowledging that it was difficult to deal with her newly diagnosed illness and its potential implications, Nancy described feeling that knowledge about endometriosis was lacking. She recalled what the gynaecologist had told her about the illness and its diagnosis:

*The thing with [endometriosis] is, they don't really know for sure and they don't really know where my uterine lining has escaped to because it doesn't show up on an ultrasound, right? So they have to do like a laparoscopy? ...And so they have to do like a diagnosis at the same time as they do the surgery to like really treat it. So it's like 'Okay...' and that leads to a lot of uncertainties.*

In saying this, Nancy highlighted the feelings that arose because of the lack of certainty offered by the gynaecologist with respect to the diagnosis and treatment of endometriosis. At other points during the two interviews, Nancy emphasized the need for research and information on endometriosis because her interactions with health care providers and others outside the medical profession revealed a lack of awareness of the illness or how it should be managed. However, she was not optimistic that research would be carried out because she felt that other people did not perceive endometriosis as warranting scarce research funding.



Nancy also gave examples of interactions with health care providers that contributed to her belief that endometriosis is not well understood. For example, she recalled a conversation in which a health care provider told her to research the disease on the Internet, rather than providing her with any information:

*When I went in there the second time for my “bladder infection”, and then he was like ‘Okay, so, ah, what do you think it is?’ I was like ‘I don’t know! That’s why you’re a doctor!’ Like ‘Hello?’ and he’s like ‘Okay, endometriosis is what it sounds like to me. Do you know what that is’... I said ‘I’m in humanities. I don’t know anything about anything.’ I was just like so mad at this guy, like being like the worst patient scenario. So, and he’s like ‘I’m going to write it down on a little piece of paper for you so you know how to spell it so you can like look it up.’ ‘Okay. Great. This is like the last day of school. I just handed in two, like, huge papers. That’s what I want to do, go home and do more research!’ (laughter) Like ‘Aren’t you supposed to tell me? Yeah, rather than Wikipedia?’ Yeah.*

These comments reveal the frustrations that arose from the lack of information about illness that she received from some health care providers. Rather than explaining to her what endometriosis is and its aetiology, Nancy was left feeling patronized and unsupported by this health care provider. Further, Nancy indicated that the wealth of information available online was somewhat overwhelming and frightening.

Upon doing research on the internet and talking with friends and family, Nancy was able to gain a better understanding of the illness that she was suspected to have. For the second interview, she brought a photograph of a book on women’s health that a friend had recommended to her. Information from this book was instrumental to Nancy gaining an understanding of possible causes of endometriosis and learning about alternative ways to treat her symptoms. Additionally, Nancy had spoken with her mother about her suspected endometriosis and learned that her mother and her aunt had both suffered from this disease. Discovering that there was a history of endometriosis in her family also helped Nancy to make



sense of what she was experiencing and lessened her feelings of abnormality to some degree.

However, Nancy reported that it was difficult to communicate with her mother about endometriosis because she did not perceive her mother as being sympathetic or supportive except with the financial costs of medication and vitamins.

In addition to having a negative effect on her relationship with her mother, Nancy also talked about the detrimental impact that being ill had on her relationship with her boyfriend. She indicated that the pain that she was experiencing altered their sexual relations. Further, Nancy reported that the birth control pills that she is taking to manage endometriosis cause her to have mood swings. She exclaimed that: *Being on hormones has just made me feel crazy. So... yeah, it's definitely caused strains on our relationship. So I don't know. We'll see how much more we can put up with this shit.* In addition, Nancy was also faced with the possibility that endometriosis could affect her fertility, which could have implications for the future of their relationship. Although her boyfriend was supportive, Nancy worried about the impact that it was having on their relationship and how it might affect their future together.

Nancy's story of endometriosis has several recurring themes related to the issues that she has encountered because of illness. Primarily, pain and discomfort made it difficult for her to carry on with her everyday activities. As well, the lack of understanding that she has encountered from health care providers has prompted her to feel hopeless that her symptoms can be managed without significant impact on her body. This lack of support from health care providers and the unavailability of peers to share her concerns with have furthered Nancy's feelings of isolation and abnormality. Overall, the two interviews that Nancy participated in offer a glimpse into the process of coping with illness that she is amidst, as she must deal with the short term effects of endometriosis and the uncertainty of its long term implications.



#### 4.10 Elizabeth

Elizabeth had just finished her second year of university when I met her just days prior to her 21<sup>st</sup> birthday. She communicated her willingness to share her story of depression in her initial email about the study, as she wanted to raise awareness of depression and to give voice to her experiences that had not been previously expressed. She talked at length about feeling misunderstood by health care providers and family members, emphasizing the need to increase awareness of the commonality of depression. In addition, Elizabeth was very interested in the photovoice component of the research and the chance to share her illness experience with others in a creative way. Elizabeth's photographs demonstrate the lasting impact that having depression has had on her life, as well as some of the strategies that she adopted to cope with it.

Elizabeth began by recollecting the time in her life in which her depressive symptoms first appeared. She described it as a *transition period* during which she had worked away from home for the summer and was about to start university in a new city. Not knowing much about depression, Elizabeth indicated that her initial reaction to her symptoms was partly determined by how she thought others would perceive her. She stated:

*I think that my initial thought of how to deal with it was to not deal with it, was to just stay isolated. It was more like it was saving face. It was like I didn't want to see people or know, yeah, I didn't want people to see me like this 'cause they probably would recognize something as being wrong or different.*

Here, Elizabeth communicated that, not knowing what to do about her symptoms, she avoided others who might recognize that she was not her usual self. She emphasized that she lacked knowledge of depression at the time and did not consider that she was susceptible to this type of illness. Further, Elizabeth believed that she would not have sought medical advice except that



she had scheduled a doctor's appointment for a minor ailment. In making such comments, Elizabeth drew attention to her past belief that depression was not something that she thought could affect her.

Elizabeth elaborated on her meeting with a doctor and the recommendations she was given for treating her depression. She said: *[The doctor] wrote me out a medication [prescription] and recommended that I find a therapist once I'd got into the city, here. I went home and I was very relieved by this because it wasn't just in my head, it was concrete, it was recognized.* Although Elizabeth's initial reaction was to ignore the symptoms that she was experiencing, she recalls in this quotation that she was relieved by the doctor's diagnosis; specifically, the diagnosis indicated to Elizabeth that there was something legitimately wrong with her and that actions could be taken to treat her symptoms. She later stated that she *wanted it gone before coming to university*, and welcomed recommendations for treatment. These comments reflect Elizabeth's desire to get past the disruption that depression was causing in her life as quickly as possible.

Depression is a mood disorder that involves the experience of: disinterest in usual activities or past-times, as well as disruptions in social or occupational functioning that last for at least two weeks (Townsend 2008, p.114). There are various types of depression and symptoms, which may include: feelings of sadness, hopelessness, dejection, and helplessness, difficulty concentrating, weakness, fatigue, over- or under-eating, sleep disturbances, decrease in motor activity, limited verbalization, and withdrawal into self (Ibid, p.117-118). Depression can have a wide range of implications for affected individuals and may lead to suicide. Various beliefs about the aetiology of depression exist, with biomedical explanations often being privileged in comparison to explanations that focus on the social, political, and economic context of



depression (Lafrance 2007; Lafrance & Stoppard 2006). In addition, higher rates of depression in women have led to theories about the influence of women's psychology, embodiment, and gender on depression (Stoppard 2010).

Despite feeling validated by her diagnosis, Elizabeth reported feeling misunderstood by the initial health care provider with whom she met because this doctor seemed to lack compassion and did not spend sufficient time explaining the illness to her. After this initial appointment, Elizabeth told her parents about her diagnosis and the medication that she was prescribed. She described her mother as reacting negatively to the idea of her taking anti-depressants, favouring therapy to medication. Because Elizabeth had not received an adequate explanation of how anti-depressants work from her doctor, she was unable to communicate this to her mother and ended up not taking this initial prescription. As a result, despite receiving therapy upon moving to the city, Elizabeth's depressive symptoms continued. She then went, along with her mother, to see a different doctor who treated her in a much more understanding way. She recalled that:

*[This doctor] said to my Mom, you know, she explained it that the brain is like an organ and she split it into four parts and she saying these four points in your daughter right now aren't functioning. You know, emotional, self-worth and I don't know what the other ones were but it was just like to me, 'Yep, that was accurate, that was true.' And I just remember my Mom crying and she was very compassionate and she's just like, you know, 'We're going to help you.' And she prescribed me Prozac.*

In saying this, Elizabeth expressed her and her mother's appreciation of the time this doctor took to explain how medication could correct the problem. In making this effort, this doctor facilitated Elizabeth's treatment and recovery, as she and her mother felt more comfortable with using medication to treat her depression than before.

Elizabeth also discussed how important her parents were to her experience of depression. In addition to participating in doctor's appointments and decisions about treatment, Elizabeth's



parents offered emotional and financial support. Although she felt that they did not necessarily understand what she was going through, Elizabeth indicated that her parents were sympathetic and did their best to show their concern. She described her mother's efforts:

*[My mom] was very concerned for the whole matter and wanting to help and wanting to reach out, and I think she'd watched, you know, Oprah and recommendations of how to deal with this and she said, you know, just like listen and that kind of thing, that's what she was trying to do but she couldn't understand that I knew it hurt her to listen to the things I was saying.*

Here, Elizabeth reveals her appreciation for her mother's concern, recognizing how hard it was to see her in that state. As such, she recognized the impact that her illness had on her family.

In addition, Elizabeth talked about how having depression affected her relationship with her sister. Upon first moving to the city to attend university, Elizabeth shared an apartment with her sister and sister's fiancé. She recalled that her sister was pivotal in ensuring her well being during this time, despite lacking an understanding of the implications that depression had for various aspects of her life. However, despite the perceived lack of understanding, Elizabeth expressed appreciation that her sister was there to take care of her more basic needs, such as cooking meals for her.

In talking about the lack of understanding that she encountered from some people at the time, Elizabeth highlighted her desire to talk about what she was going through. Although she attended several therapy sessions with an array of therapists, she described the value of having others with whom she could relate. The most beneficial support that Elizabeth talked about came from the few people she met who listened and empathized with her experience. Specifically, she reported that one friend was a significant source of compassion, as were the members of a support group that she attended a few times. Even though this support group was composed of much older individuals, Elizabeth felt that they shared her desire to talk about their experiences



without being judged. Thus, Elizabeth found comfort in talking with others who could relate to her experiences, which diminished the sense of isolation and difference that she was feeling.

While Elizabeth indicated that she has since recovered from depression, she talked about the healing process and the ongoing impact that depression has had on her life. She described having depression as a *hindrance*, leaving a lingering effect on her life. For example, Elizabeth described how there were times when she had to disclose her history of depression, such as on the medical form for a program that she was applying to. She acknowledged the stigma that is often associated with depression and mental health issues, stating that depression is sometimes like *a skeleton in [her] closet*. However, Elizabeth also stated that she wanted to use her experience to lessen the silence surrounding this illness, and expressed an interest in pursuing a career in alternative therapy. In this sense, Elizabeth is drawing on her experience of depression to find greater purpose and meaning in her life.

Elizabeth's story describes what it is like to experience depression as a young woman going through important life changes (meeting new people, moving to the city to start university), and the effects that illness can have on roles and relationships at this time of life. Elizabeth reported often feeling misunderstood and observed a need for greater awareness of and openness about depression, which was a motivating factor in participating in this study. In addition, her experience of depression has led her to become interested in certain classes in university, and may influence the career path that she takes in the future. In these ways and others, illness has left a lasting impression on Elizabeth. Thus, although Elizabeth perceived her depression as having been treated, she continues to negotiate the implications of her history of depression and its lasting impact on her life and identity.



#### **4.11 Melanie**

Melanie, age 33 at the time of our first interview, was the sole participant in the study with children, as she and her husband had a six year old son and a three year old daughter. Throughout her story, Melanie framed much of her experience of breast cancer with respect to her role as a mother. She repeatedly talked about the necessity of coping in order to care for her children, and that they were her motivation to persevere against breast cancer. In addition to her children, Melanie talked about a number of other people who were instrumental to her survival because of their caring and support, including her husband, mother, sisters, in-laws, and friends. As a whole, Melanie's experience highlights the impact that illness has had on her roles and relationships, as well as her approach to life.

Melanie began by recounting her initial health concerns and how this led to a breast cancer diagnosis. At the time, Melanie was pregnant with her second child and had discovered a lesion along with discharge from her breast. Initially, Melanie was told by health care providers that she was pre-lactating. Following the birth of her daughter, the issue continued and she sought further medical advice from a lactation consultant who investigated the matter. After being told that breast cancer was a possibility, Melanie met with her family doctor, who immediately sent her for a mammogram and ultrasound because of the history of cancer in her family. Her symptoms, combined with the discovery of a calcified area, led to an appointment with a specialist the following week and a biopsy the week after. Two weeks later Melanie received the biopsy results and was diagnosed with a form of breast cancer called ductal carcinoma in situ, and a week later had a mastectomy on her right side.



When I asked about her reaction to the screening that she underwent, Melanie responded:

*When I had my mammograms and stuff done I wasn't thinking then that it was serious, but when I got the call within two hours from my doctor saying 'There might be something there.', that's when I was thinking, you know, 'What the hell? What else could happen?' because just before that, like when I had my daughter with her being early, I actually haemorrhaged severely after having her and I lost five and a half pints of blood and they nearly lost me, and then they nearly lost her three times when she was in the NIC-U so it was just an emotional roller coaster over and over again sort of thing. I'm just thinking 'Okay, you know, what? What else is it gonna be? What, what now? Is it gonna be this? Is it gonna be that? What else is gonna happen?'*

In saying this, Melanie identified the myriad of health issues that she and her daughter had recently experienced. She continued on to say that the possibility of a breast cancer diagnosis was unexpected, as she and her health care providers initially believed that her symptoms were related to lactation. As a result, Melanie faced a challenging situation in which she questioned what else could go wrong in her and her family's lives.

After her diagnosis was confirmed, Melanie had a mastectomy, and thus did not require radiation or chemotherapy. She suggested that her family responsibilities prompted her doctors to schedule her surgery as soon as possible. Melanie considered herself lucky that the cancer was caught at an early enough stage that, by having a mastectomy, she did not require radiation and chemotherapy, and therefore could quickly return to her role as caregiver for her two young children. Despite being able to resume her family roles quite quickly following surgery, Melanie indicated that her mother and in-laws offered critical support. She said: *We had family come and we were lucky that it was a time where harvest was done, it wasn't during the seeding, you know, My father-in-law's shop had slowed down so my mother-in-law could come and help and, you know, we lucked out.* In addition, Melanie's two sisters were key sources of support, helping out as much as they could over the winter holidays. Although she was successfully able to negotiate the care of her children during her recovery from surgery, Melanie suggested the need for



assistance with childcare for families with young children who are dealing with serious illness, as well as the availability of counselling services for all family members.

As well as discussing the support that she had received from her mother and sisters, Melanie indicated that her breast cancer diagnosis affected her family member's lives in other ways. Foremost, Melanie related how hard it was to tell her mother that she had cancer because of other family member's experiences with cancer. She expressed that:

*I didn't want to tell her. To tell you honestly, I did not want to tell her because we'd gone through so much with dad and with her brother, and actually her mom as well because she has a brain tumour. So we had gone through so much stuff, I was just like 'I don't want to tell her.' And even with the kids and I'm like 'Kay, I don't want to tell her, but I'm going to have to tell her because everything's going on.' But when I did tell her she cried and cried because she didn't want to lose another family member, but she got over it. She helped out, yah, she was really good. The biggest thing was she just cried for a really long time.*

Here, Melanie communicated the emotions that she felt disclosing her cancer diagnosis to her mother, knowing that her mother had gone through cancer with other family members including Melanie's dad who died from his third bout of cancer. In response to her mother's emotional reaction, Melanie revealed that she informed her mother that she would be okay, which helped to alleviate some of her mother's anxieties. However, Melanie reported that her mother continues to be concerned for her health and that of her two sisters, encouraging them to seek medical advice for any sign of illness.

As a result of having breast cancer, Melanie reported that her relationship with her body had changed. Specifically, she experienced a heightened awareness of her body and the changes that had taken place. For example, Melanie was self conscious of her bodily appearance since having a mastectomy, and worried about how she looked in clothing and a bathing suit. Another way in which Melanie was more aware of her body was in relation to her health. She indicated



that she now pays more attention to leading a healthy lifestyle, and has cut back on unhealthy behaviours and increased healthy behaviours. Further, Melanie felt that her efforts to be healthier had been a positive influence on her family's health, as her children were learning good eating habits.

Melanie also was vigilant in checking for signs of further cancer, and sought out screening for cancer in the other breast and elsewhere in her body. Melanie said:

*I was told that I have a high chance of probably having a recurrence... It was the surgeon who said it. He said that I have a high recurrence of it because I did get it so young, that I could have a good chance of having it come back later in life... And it could be a family thing too on that note. He didn't really elaborate but it could be. And I think that with the type that I did have, because it was still in situ, because we caught it before it became invasive, that if it would have become invasive and then there would have been a chance of it spreading further, so he's pretty, pretty confident that nothing did spread anywhere else, but (fades off).*

In saying this, Melanie conveys the risk she perceives of having a cancer recurrence. While she was not sure of the exact reason, she indicated that the surgeon told her that recurrence was a likely possibility. However, Melanie also noted that the type of breast cancer she had was not invasive and therefore there was less chance it had spread to other parts of her body. From these comments and others, it was evident that Melanie was concerned about her risk of recurrence, but also wanted to downplay its likelihood. She summed these feelings up by saying: *I worry about it, but if it happens, it happens.*

Despite the changes that had occurred in Melanie's life due to breast cancer, she was able to find benefits in the illness experience. On one hand, having gone through breast cancer confirmed to Melanie that she had made a good decision to apply to nursing school. She believed that her experiences would allow her to empathize with the patients that she cared for, and possibly give hope to other young women facing a similar situation. In addition to striving to



become a nurse, Melanie wanted to raise awareness of breast cancer, particularly among younger women. She described her willingness to talk with others about her experiences so that others would realize that breast cancer is not specific to older women. One way that Melanie was involved in raising awareness and money for breast cancer was through a calendar put together by a sports team that she belonged to. In addition to using her illness experience to raise awareness, Melanie has also gained new insight into life. She indicated that she makes greater efforts to enjoy life and spend time with her family. Thus, Melanie emphasized that cancer does not mean the end of one's life, instead viewing it as a *road bump* in the much longer life course that she envisions for herself.

#### **4.12 Summary**

The above stories about the participants offer insight into their individual experiences of illness, highlighting the process by which they became aware of their illness, how it was treated and managed, and the effects that it had on their everyday lives and well-being. I provide these holistic accounts of the participants' stories in order to familiarize the reader with each of the young women. These accounts of participants' experiences also allow for comparisons and general observations to be made across the interviews.

First, while rapport was easily established with most participants, often because some communication had typically taken place regarding illness and the study, the interview format and length varied. The interviews with Nicole were the shortest, lasting 45 minutes and 60 minutes respectively. In addition, I participated to a greater extent in these interviews and in those with Aurelie than in the interviews with other participants because they were less



forthcoming and required that I ask specific questions and for elaboration. Despite their succinctness, both Nicole and Aurelie spoke with great openness about the challenges that they faced and continue to face in their lives as a result of illness. In comparison, Stacey, Nancy, Leanne, and Melissa were very forthcoming, all of whom talked at length about their experiences of illness without much prompting from me. The interviews with Laura, Elizabeth, Melissa, and Sandra fell in the middle in terms of my participation in the discussion, with some questions being interspersed throughout their responses. Melissa and Sandra were the two participants who participated in one interview each, however these interviews were very detailed and lasted for 83 and 118 minutes respectively.

While many similarities among participants emerged during the interviews, each participant had one or a few themes that stood out as prominent in their experiences of illness. Stacey, Laura, Nicole, and Nancy raised issues related to the negotiation of illness with respect to relationships with partners, and specifically the possibility that illness could prohibit them from having children. As well, all of the participants discussed the impact of illness on their family members, particularly with respect to the concerns that illness raised. Some participants also called attention the need to manage issues of independence during the illness experience, as was particularly the case for Leanne and Melissa. Participants also commonly described strained communication with family members and/or friends, as seen in the stories of Stacey, Laura, Nancy, Elizabeth, Nicole, and Leanne.

Another common theme was related to the uncertainty of the future for several of the participants. For example, Sandra, Nancy and Nicole were uncertain of the long term implications of illness, while Stacey, Laura, Aurelie and Melanie all faced the possibility of a cancer recurrence. While the majority of participants had received a definitive diagnosis and



were receiving or had completed treatment, Melissa remained unsure regarding her two illness diagnoses and the best treatment options. As such, Melissa experienced uncertainty on a number of fronts and was less advanced in making sense of her experiences, although she shared many similarities with Nancy and Sandra as well. In contrast, the two participants who experienced mental illnesses, Leanne and Elizabeth, viewed their illness experiences as having ended more so than other participants, despite that mental illness also had ongoing implications for their lives.

Discussions of physical changes and limitations were also common in many of the participants' stories of illness. While Stacey, Laura, and Melanie focused on having experienced the loss of a breast, other participants discussed the limitations or restrictions introduced by illness, specifically when they prohibited or could potentially stop them from doing past activities. Discussions about limitations or potential restrictions were most prominent in the stories of Aurelie, Nicole, and Melissa, while Leanne and Sandra placed less slightly emphasis on this topic. Elizabeth was the sole participant who did not experience significant changes in physical appearance or ability, but nonetheless reported that depression had physical and psychosocial implications.

The similarities and differences between participants that I briefly describe here will be further elaborated in Chapters Five, Six, and Seven. I now turn to this thematic analysis of participants' experiences and the insight offered into what it is like to be seriously ill during young adulthood. In Chapter Five, I address participants' embodied experiences of illness. Then, I explore the temporal and relational aspects of participants' experiences of illness in Chapter Six, followed by a discussion of how illness was made sense of in Chapter Seven.



## **Chapter Five – Exploring Participants’ Embodied Experiences of Illness**

*I just feel bad for my body... like I wish that it worked the way it's supposed to work. (Sandra, Multiple Sclerosis)*

### **5.1 Introduction**

In this chapter, I describe participants’ experiences of serious illness with a specific focus on the process of coming to be ill, and the impact that illness has had on their everyday lives. I have divided the chapter into two broad themes, each of which has sub-themes that elaborate on the broader theme. The two themes are: discerning and learning about illness, and disruptions and limitations arising from illness and its treatment. The sub-themes of the discerning and learning about illness theme are: the onset of illness, receiving/obtaining a diagnosis, and information about illness. The sub-themes of the theme on disruptions and limitations arising from illness are: treatment as disruptive to everyday life, incorporating medication into everyday routines, negotiating limitations due to illness and treatment, and managing physical changes and the relationship with the body. These themes highlight a variety of issues experienced by the participants, some of which have been reported in the existing literature, emphasizing their pertinence to young adult women across different serious illnesses. However, in this chapter, I seek to more clearly elucidate participants’ lived experiences of illness and its resulting implications in order to gain a better understanding of what it is like to be seriously ill during this life stage. By focusing on their lived experience, I seek to represent the essence of serious illness for the participants and understand how they made sense of the bodily changes that they experienced and their implications for their everyday lives. Some of the photographs taken by participants are included along with corresponding quotations in the discussion of the themes



that emerged from my analysis; however, some photographs are not included in the following analysis because they are repetitive or unrelated to the major themes and sub-themes.

## **5.2 Discerning and Learning About Illness**

This theme explores participants' initial experiences of illness and how they came to learn about illness through the signs and symptoms, and in the diagnostic process. I briefly discuss the experience of signs and symptoms of illness in the first sub-theme, followed by a description of how participants obtained or received a diagnosis from health care providers. While the process of diagnosis varied immensely, this sub-theme highlights similarities in experience and coping with diagnosis. The third sub-theme builds upon the prior two by highlighting the various ways that participants gained information about illness and its impact on the coping process. Overall, this theme explicates the process of discerning and learning about illness that was set in motion when participants experienced a disruption to their lived body (van Manen 1990), causing their body to move to the fore of consciousness and to no longer be taken for granted (Leider 1990, cited in Nettleton 2001, p.53). As a result, participants sought to make sense of their bodily experiences through medical consultation and gathering information about illness.

### ***5.2.1 Experiencing Signs and Symptoms of Illness***

Many of the participants started their stories of illness by describing the initial signs or symptoms of illness. In doing so, these participants highlighted how they came to observe signs



or symptoms of illness, as well as their initial reactions to out-of-the-ordinary changes in their health and/or the possibility of illness. For some of the participants, initial signs or symptoms of ill health appeared suddenly, while others observed or underwent more subtle bodily changes. However, all of the participants indicated that the onset of illness was marked by some change in their physical or mental state, or both, which disrupted the taken for granted nature of their bodies and everyday lives. In response to their out-of-the-ordinary experiences, many participants drew upon what phenomenologists call ‘typifications’, or the “socially constructed abstractions and simplifications of the complexity of experience that enable us to handle it in a regular, organized, and socially shared way” (Bentz & Shapiro 1998, p.50, cited in Bentz & Rehorick 2008, p.17-18). In other words, participants sought familiar explanations for their symptoms in order to explain their bodily experiences. The following paragraphs expand on the recognition of illness and how participants sought to make sense of the initial signs and symptoms of illness.

Although the young women in the study experienced a wide range of symptoms and signs of illness that were both unique and shared, they each experienced a bodily sensation or event that was out-of-the-ordinary. For some participants, the onset of illness was quite sudden, and came in the form of an episode of acute ill health. For example, Nicole and Aurelie’s each experienced a seizure that led to immediate medical attention. Aurelie described her experience:

*I was shaking, it’s like a convulsion... and you can’t control it and, uh, you can’t control your arm and so it’s, um, it’s so frightening because you are [conscious], but in the meantime you have a lot of images that come... And after you, you fall on the floor but you are still conscious. So I am fine but I can do nothing to, to control it and, uh, after I just lost my conscious[ness] but, ah, for 2 or 3 seconds, but it seems like 1 hour for me.*

Her comments emphasize the loss of control over her body that she experienced because of this initial sign of illness. As such, Aurelie was thrust into a frightening state of being in which her



body was acting in an unfamiliar way that was out of her mind's control. Nicole described having a similar experience, which was preceded by an aura, or disrupted vision. These participants' descriptions provide evidence of the initial onset of illness brought about a separation between the mind and body (Good 1994; Williams 1996, cited in Seale 1998, p. 25). As such, the participants became acutely aware of their bodies because they no longer existed in their prior taken-for-granted or 'absent' way (Leider 1990, cited in Nettleton 2001, p.53).

Other participants experienced a less sudden onset of illness, and thus made attempts to understand what was happening with their bodies. For example, Melissa remembered: *I woke up one morning and I was extremely dizzy and I was so dizzy I couldn't get out of bed and I called into work and said 'Look, I can't come in. I think I must have caught some flu or something 'cause,' I said, 'I can't get off of my bed, like I'm so completely dizzy.'* In saying this, Melissa recalled how the onset of illness was experienced as a profound shift in her health status. Sandra had a similar experience, indicating that she experienced numbness that spread over time to almost the entire left side of her body. Because their symptoms disrupted the taken-for-grantedness of their bodies and everyday lives, both Melissa and Sandra sought to make sense of them with respect to past health issues and existing knowledge about illness. Specifically, these participants downplayed the possibility of serious illness and considered the possibility that they had more common ailments, such as the flu, a pinched nerve, or shingles.

Attempts to normalize or minimize symptoms were evident in the stories of Nancy and Laura, who also did not initially consider the possibility that their symptoms were signs of serious illness. In Nancy's case, she believed that the pain that she was experiencing was a sign of a problem with her intra-uterine device, a bladder infection, or kidney stones. Laura reported her belief that the lump in her breast could not possibly be a sign of cancer, stating that she



ignored it for some time until the difference in size between the two breasts became undeniable. In trying to understand their bodily experiences, these participants attempted to reassure themselves that their symptoms were insignificant or evidence of a minor (treatable) health concern. Thus, the participants drew upon familiar explanations or meaning structures for their out-of-the-ordinary bodily occurrences, as is common when individuals find themselves in unfamiliar situations (see for example, Ellis 2002; Rehorick 1986). Further, Laura convinced herself that the possibility of having a serious illness like breast cancer was unlikely because of her age, a belief that was shared by the health providers with whom she eventually consulted. Stacey and Melanie also recalled similar doubts with respect to their discovery of initial signs of breast cancer, however they did not dismiss this possibility to the same extent as Laura and consulted health care providers regarding their concerns. Thus, some of the participants employed “effortful possibilizing” (Zaner 1981, cited in Rehorick 1986), in that they considered the possibility that they had a serious illness among other likelihoods.

Elizabeth and Leanne had unique experiences of the onset of illness in comparison to the other participants, as well as one another, although both experienced symptoms that were manifest in their behaviour. For Elizabeth, she experienced social withdrawal, apathy, lethargy, and a desire to sleep all the time, which greatly affected her everyday life. As such, she recognized these physical and psychological changes as evidence that something was different with her embodied self. While Leanne also exhibited behavioural changes, her psychological state was such that she did not recognize that she was ill. She explained this by saying:

*I was sick. My brain was crazy. The best way I know how to describe it is taking someone who has like OCD, someone who's suffering from dementia, someone who's suffering from Alzheimer's, someone who's suffering from ADHD, and put it all together and that was my head. I was fixated. I had to exercise.*



As she described in this quotation, Leanne's illness affected her psychologically to a great extent. However, her physical appearance divulged her anorexic behaviour to others, which ultimately led her family members to intervene and ensure that she received health care attention.

The above discussion of the symptoms and signs of illness that were experienced by the participants highlights their initial encounter with illness, as the young women faced a body that did not feel or function in its previously taken-for-granted way. Participants' comments offer insight into what it was physically and psychologically like to experience the early stages of serious illness, experiences that may be shared by individuals of all ages. In particular, the participants gave voice to the embodied experience of their symptoms, providing descriptions of what they experienced and how they interpreted the initial symptoms of illness. In some participants' stories, common themes are evident related to: the unexpectedness of symptoms and attempts to normalize or minimize symptoms. In most cases, participants considered possible explanations for what they were experiencing, trying to make sense of their experiences with respect to past experiences or existing knowledge, known to phenomenologists as 'typifications' (Bentz & Shapiro 1998, p.50, cited in Bentz & Rehorick 2008). Leanne's experience was unique in that her psychological state prohibited her recognition of illness, although her family members made sense of her unfamiliar behaviour in a similar way as the other young women. The powerful descriptions provided by participants that are cited in this section and Chapter Four offer insight into the array of emotions that they experienced, as the signs and symptoms of illness were unfamiliar to most and brought about feelings of confusion, fear, anxiety, and uncertainty. Next, I turn to participants' recollections regarding their diagnoses and how they reacted to them.



### 5.2.2 Receiving/Obtaining a Diagnosis

Each of the participants recalled the process by which their diagnosis of a serious illness came about. Their experiences varied tremendously with respect to how and within what length of time their diagnoses came about. In the cases of Stacey, Laura, Melanie, and Elizabeth, concerns over symptoms were raised during routine contact with health care providers or during appointments for other health-related issues, as is often the case for chronically ill individuals (Charmaz 1991). Characterizations of young adults as healthy and/or invincible may contribute to the failure of this population to be proactive in seeking medical advice regarding health concerns (Albritton & Bleyer 2003; Miedema et al. 2006). Thus, contact with health care providers for other reasons yielded the opportunity to raise concerns about symptoms, which proved to be significant to the diagnosis of illness for these four participants.

However, diagnosis did not necessarily follow the solicitation of medical advice and, in some cases, consultations with health care providers supported the normalization or minimization of signs or symptoms of illness. Specifically, participants were met with cautious responses from health care providers who seemed to want to avoid causing unnecessary anxiety in their young patients. For instance, Stacey, Laura and Melanie were all told that there was a slim chance that they had breast cancer because of their young age, although each of them were later diagnosed with the illness. For example, Melanie recalled the response of health care providers to her symptoms:

*They just kinda sloughed it off, “Oh well, you’re just pregnant.” And to me that just kinda seemed really weird. And because of my age, is the biggest thing, ‘cause I was 30 so they didn’t even factor into it that it would even have been breast cancer because of that. And when my GP felt my breast, I didn’t have a lump so he didn’t really know for sure. So it was just trying, let’s do something exploratory and see what it is.*



Despite the reaction that she encountered from many health care providers, Melanie pushed for an investigation of the lesion and discharge from her breast after she had gave birth to her daughter. Due to her persistence, a potentially problematic area was discovered in Melanie's breast, which led to an appointment with a specialist, a biopsy, and a diagnosis of breast cancer. Although such a diagnosis was unexpected and upsetting, Melanie was thankful that she had persisted with medical tests so that the cancer was caught before it became invasive.

Laura also discussed how her initial concerns about the lump in her breast were downplayed by health care providers, which prompted her to believe that it was not problematic for almost two years. After deciding that the lump should be investigated further as it had become painful, Laura went for a mammogram. She then recalled the appointment that she had the following day:

*The words that were used in the report, 'cause they faxed the report from the radiologist right away, some of the words stuck out like, um, the tumor was, uh, crystallized in, or like crushed glass I think is the terminology they use, uh, which is ultimately a bad sign... Just certain phrases like the lymph nodes, there [were] five to six that were enlarged on the ultrasound and, um, yeah, just all these things like 'Oh that's not good, oh that's not, that's really not good. Um, so I guess I also approached it in a little bit of a, not technical but trying to hold onto words instead of feelings, I guess.*

Laura described this memory and her efforts to approach her diagnosis from a scientific perspective rather than an emotional one in order to cope with, what she described as, the *disbelief, [and] gripping fear* that accompanied her diagnosis. She later articulated these feelings by saying: *The monster that had been kind of lurking in the closet or under the bed was there... all of a sudden it was like staring me in the face.* Through the use of metaphorical language, Laura emphasized that her worst fears had come true after years of denying such a possibility.



The issue of delayed diagnosis in young adults with cancer has been identified in the existing literature and is thought to be related to health care providers' lack of familiarity with and hesitancy to diagnose cancer in young people, in addition to young people's inaction regarding health concerns and often vague symptoms (Albritton & Bleier 2003; Grinyer 2007; Miedema et al. 2006). Further, signs and symptoms of serious illness may be overlooked in young people affected by other illnesses, as is reportedly the case for women with endometriosis, many of whom experience delayed diagnoses due to beliefs about age and menstruation (Cox Henderson, Andersen, Cagliarini, & Ski 2003). In accordance, Nancy's initial encounters with health care providers yielded the suggestion that her symptoms were normal aspects of menstruation, demonstrating how the possibility of a serious illness was not considered by emergency room doctors. Thus, Laura and Nancy's experiences, along with existing research, suggest that narrow-minded health care providers or those who are cautious in suggesting potential diagnoses can contribute to the perception that young people are unlikely to be affected by serious illness, which may discourage young adults from further contact with the health care system regarding signs or symptoms of illness.

While some health care providers were more cautious in suggesting possible causes of participants' symptoms, others offered their beliefs about tentative diagnoses more openly. For example, Sandra was told by a doctor at a walk-in clinic that she likely had either a brain tumour or multiple sclerosis and would need to consult a neurologist to have her symptoms investigated. Therefore, from that appointment on, Sandra and her mother indicated that they knew that she was dealing with something serious, which was confirmed after medical tests to be MS. Aurelie had a similar, but slightly different, experience in which she was eventually diagnosed with a malignant brain tumour after the possibility of epilepsy and a benign brain tumour were ruled



out. Despite that this experience was frightening for Aurelie, she indicated that she approached her diagnosis from a scientific perspective, similar to what Laura said, and remained optimistic because that is her personality. Stacey recalled the benefit of a realistic attitude, saying : *It's funny, every time I go for surgery [the doctors] always tell me that it's probably nothing, and I always tell myself it's probably something. So [the second time], they took out this lymph node and sure enough it was cancer, um, breast cancer again.* Thus, although these participants experienced a variety of emotions throughout the diagnostic process, the admission that they may be affected by a serious illness was significant in allowing them to prepare for such a diagnosis and initiate coping mechanisms.

Melissa also went through a process of trying to obtain a diagnosis from health care providers, and expressed appreciation for those who were upfront with her about the possible causes of the symptoms that she was experiencing. After undergoing medical tests, Melissa indicated that the hardest part was *waiting and wondering* to see if she had a life-threatening illness for three months, upon which she was told that she did not. Following these tests, Melissa was then told by the neurologist to *start all over* with her family doctor in trying to obtain a diagnosis. This led her to consult an alternative health specialist who was the first to recognize her ill health:

*She was the first person who, um, finally admitted that I was sick. And I think that was a first step, when I saw her, and she does blood analysis and, uh, when I saw her that day I was just completely exhausted and she did this blood analysis and as soon as she told me, she's like 'You are one very sick girl.' and I just burst into tears because for me that was the first time of being told that, from somebody in a health care profession that I actually was sick and it wasn't in my head. And so it gave me more hope actually, 'Okay we can treat something because now there is something there to treat.' ...She said that my body, my organs were starting to shut down at that point when I had saw her and the medical doctors said there was nothing wrong with me... So it's so conflicting and you think about it, like it's huge, because it's, it's, I mean 'You're completely healthy.' versus 'Your organs are shutting down.' Like, it doesn't even register on the same scale.*



Melissa emphasized the ‘diagnostic relief’ (Charmaz 1991) that she experienced when her symptoms were confirmed to be legitimate signs of illness. Through further consultations with this alternative health specialist and a naturopathic doctor, Melissa was diagnosed with primary hypoadrenalism and secondary hypothyroidism. Thus, unlike many of the other participants who experienced their diagnosis as unexpected and disruptive, Melissa welcomed the confirmation of illness after years of medical appointments, as it legitimized her symptoms and enabled her to formulate a plan to deal with her illness, a sentiment that Elizabeth also expressed.

Melissa’s experience with health care providers is similar to that of women of various ages who exhibit vague symptoms that do not point to a specific cause. Particularly, because medical tests failed to lead to a diagnosis for Melissa, health care providers began to question her reports of symptoms and suggested a psychosomatic component to her health problems. This experience is similar to what is reported by individuals experiencing medically unexplained illnesses (Charmaz 1991). In particular, women with chronic pain are often met with scepticism, belittlement, and blame by health care providers (Werner & Malterud 2003), especially because it is difficult to verify chronic pain (Good 1994). Thus, although Melissa was eventually diagnosed by an alternative health specialist with two illnesses, her symptoms went largely untreated as the traditional health care providers that she consulted struggled to identify a specific cause to the pain and dizziness that she was experiencing.

In the cases of Nicole, Leanne and Elizabeth, they were given more definitive diagnoses by their health care providers upon assessment of their symptoms. However, none of these young women indicated that adequate support was initially received to manage the diagnosis, which was particularly problematic because they and their family members were unfamiliar with and



ill-equipped to deal with illness. For example, Nicole recalled receiving a diagnosis after two days in the hospital: *[The doctors] basically said 'You've got epilepsy.' and gave me like a pamphlet about it and that was kind of it. They didn't sit down and talk to me, like I don't imagine they have time to sit down, but I didn't really feel that, um, that they really wanted to explain anything to me.* Nicole indicated that her diagnosis was difficult to accept because of the rapidity with which it occurred and its inconsistency with her identity as a young woman. Specifically, Nicole did not identify with the ill status that she was labeled with by doctors because she had only experienced one seizure and was otherwise in generally good health. Her experience calls attention to the difficulty that young people may have in adjusting to the idea of having a serious illness, particularly when the onset of symptoms is shortly followed by a diagnosis and little time is available to integrate a changed health status into self identity.

Further, Nicole's diagnosis came with little information about what she should expect with respect to illness, which required her to look elsewhere for this type of support. Elizabeth also had a similar experience, receiving a prescription and a stack of pamphlets from the health care provider who initially diagnosed her with depression. She described this experience as overwhelming and indicated that the doctor's failure to explain how depression could be treated with anti-depressant medication left her feeling as if her illness had not been taken seriously. Further, Elizabeth's uncertainty about the prescription for anti-depressants that she was given meant that she was unable to explain to her mother how such medication could benefit her. As such, she did not take this initial prescription and continued to experience depression. Therefore, Elizabeth's experience suggests that a lack of understanding and involvement in treatment decisions may negatively affect treatment compliance, which already suffers among young people (Badlan 2006; Rosina et al. 2003). However, both Nicole and Elizabeth sought out



different health care providers in the future in order to obtain information and support regarding illness and its treatment.

Leanne's diagnosis was similar to Elizabeth's in the sense that the initial doctor that her mother brought her to meet with was able to quickly diagnose her symptoms as evidence of anorexia. However, Leanne reacted very differently than Elizabeth, not accepting the diagnosis or wanting to make changes in her behavior. She remembered:

*[In] April, I saw this doctor who supposedly specialized in eating disorders and her thing was 'Just get her to eat. Eat everything. Eat as much, you know, just make her eat.' So I did, because I was at home and I had to, I had no choice. So I started eating and I gained like 30 pounds. It didn't look like it but on the scale that's what it said... I was freaking out. I put [my family] through hell because I didn't care... I just wanted to exercise and I just wanted to go to school.*

Thus, while her mother tried to help Leanne overcome her illness by following the doctor's advice, she was not given the resources or support to deal with the psychological component of anorexia. As a result, Leanne's over-exercising and under-eating took a greater toll on her physical health leading to her hospitalization and near-death.

The lack of support upon diagnosis that was communicated by Elizabeth, Leanne and Nancy demonstrates how insufficient support can contribute to the questioning of the diagnosis and/or the treatment received from health care providers. Thus, these participants' experiences demonstrate the importance of information and support from health care providers, as an illness diagnosis or treatment may be hard to accept without a proper understanding of it. The value of information to coping with illness has been widely recognized (see for example, McCaughan & McKenna 2007; van der Molen 1999), as has the benefit of support from health care providers for young people with cancer (Kyngas et al. 2001). Thus, inadequate information may be



detrimental to young people affected by illness, who may be unsure of where to acquire information or have trouble determining the credibility of information (Juvakka & Kylma 2009).

The above paragraphs offer insight into how the diagnosis of serious illness came about for the participants, and how they reacted to their diagnosis. Although many health care providers, and often the young women, did not perceive serious illness as being likely during young adulthood, their diagnoses demonstrate that it is possible. Common themes that emerged in the stories of some of the young women with respect to diagnosis include: the possibility of delayed diagnosis because of young adults and/or health care providers' perceptions, the benefit of health care providers' openness about the possibility of such a diagnosis, the importance of support and coping strategies to coming to terms with illness, and the desire for legitimization of symptoms by health care providers. This discussion highlights the need for sensitivity in the diagnostic process, as young adults may experience the onset of illness as unexpected and may not have prior experience with ill health (Politi et al. 2007). Further, the young women who felt that support was available from health care providers also seemed to cope better with their diagnosis than those who did not receive adequate care and support. The next sub-theme focuses on gathering information about illness, which builds on this discussion of diagnosis and coping.

### *5.2.3 Gathering Information About Illness*

Upon their initial experience of symptoms and signs of illness, many of the participants began searching for information regarding potential illnesses. The acquisition of information continued after initiating contact with the health care system. In some cases, consultations with health care providers were a major source of information for participants regarding their



diagnosis or tentative diagnosis. In other cases, health care providers did not provide adequate information, as mentioned previously, and the young women were required to look elsewhere for information about illness. Often, participants were able to find the information that they were looking for; however, some informational needs were reported to be unfulfilled. The following paragraphs discuss the sources of information identified by participants, the adequacy of information acquired, and the need for further information.

A few of the participants noted that health care providers were crucial sources of informational support during their illness experience. For example, Aurelie indicated that she learned about her illness and its treatment from talking with the doctors and nurses, commenting: *[The] doctors explain to you very well... they're all so nice, so you can ask questions.* As well, she said: *Because I'm more scientific... I wanted the nurses to explain all the things, all the machines, how it works and what it does to me.* Having access to information regarding brain tumours and their treatment was important for Aurelie, who used this medical information to help her to understand what she was going through.

Elizabeth also reported the value of information provided by health care providers. Although she initially felt unsupported by the doctor who diagnosed her with depression, a second doctor with whom she consulted took the time to explain to her and her mother how the brain may be affected when someone is depressed. The explanation offered by this doctor regarding depression and the purpose of medication was pivotal in Elizabeth's treatment, particularly because her mother was initially opposed to the use of anti-depressants. Thus, in gaining a better understanding of the physiological aspects of depression, Elizabeth and her mother were able to make better informed decisions about its treatment. Similar to Elizabeth, the deficit that Nicole originally experienced in informational support from health care providers



was later compensated for by her family doctor, who continues to offer informational support and explain the tests results received from her other doctors. Thus, Nicole's experience highlights the important role that family doctors may play in providing information and helping their patients to navigate the health care system.

In addition to obtaining information from health care providers, several of the participants accessed information on illness via the internet, and from illness-related organizations and books. Participants' family and friends also helped in searching for information about medications, treatments, and implications of illness. Similar to Sandra and Elizabeth who received input from family and friends regarding possible treatments, advice from a friend regarding an information source proved to be crucial for Nancy, particularly because she received insufficient information from health care providers regarding her diagnosis. For example, she was told by one health care provider to research endometriosis on the internet. Nancy explained the photograph below in relation to her informational needs:





*This is the book that was, um, recommended to me by a friend: 'Women's Body, Women's Wisdom.' This big thick bible book, which was like... it's really good. She's like, this lady is like a really awesome doctor who knows a lot about medicine but also knows about energies and stuff. So yeah, she's awesome. And ah, like the doctors, like when they, um, like my gynecologist, when she diagnosed me just said 'Okay, take hormones.' and didn't say to do anything else. Whereas this book was like 'Okay, you have to change your diet. You have to stop eating meat and dairy and all these things that have extra hormones in them.'*

In addition, Nancy noted that she valued the explanation of the aetiology of endometriosis offered in this book because it was beneficial to her understanding of the illness, which will be discussed further in Chapter Seven.

Other participants also commented about other sources of information regarding illness that were useful. Both Sandra and Aurelie mentioned that they had consulted a handbook produced by support organizations related to their respective illnesses (MS Society, Brain Tumour Foundation of Canada), which offered information on illness, its treatment, and potential impact on everyday life. Participants such as Elizabeth, Sandra and Laura talked about researching illness at the library or in textbooks from university classes. Sandra also consulted with other individuals via internet forums, as did Laura, to learn more about what to expect from treatment. Additionally, Stacey and Laura talked about how attending conferences for young women with breast cancer provided access to research and advice from others with similar experiences. Thus, participants found various ways of fulfilling their informational needs, which was a key component of the coping process.

Although understanding the physiological and medical aspects of their diagnosis was important to some extent, the prevailing informational needs discussed by participants were related to practical aspects of managing illness. Stacey articulated this need when discussing her role as a peer supporter:



*A lot of the things, um, that we'll talk about are things that you can get answers in clinical terms but people want to hear it from someone else who, you know, has been through something similar. For instance, like, you know, 'How did you find a bra that worked with your prosthetic?' - if that's what you're having to do afterwards. Or, um, you know, 'Did you end up going into menopause while you were in chemo?', 'Did your period come back?', 'How long does it take?', um, 'What did you do, um, while you were waiting for your hair to grow back after chemo?', um, things like 'Nobody told me that when my hair fell out during chemo that my head was going to be really sore that week, that it was gonna feel like my scalp was bruised.' Um, you know, just simple stuff and it's not that your doctors are omitting these things, they just don't know 'cause they haven't experienced them or it's a small detail compared to the life-and-death stuff that they're telling you about.*

Stacey highlights the importance of having access to information regarding what can be expected following diagnosis, during treatment, and in the future. In particular, she suggests that individuals who have similar experiences can be critical sources of practical information that health care providers may be unaware of or may not have time to discuss. Aurelie also indicated that accessing practical information regarding treatment was crucial for her, as she greatly valued the knowledge and experiences shared by others going through treatment and the members of the brain tumour support group that she attended. On the other hand, not all participants felt that practical information and advice from others affected by their respective illnesses was available.

For most of the participants, learning more about illness was a vital part of the coping process and helped to restore some of the young women's sense of agency that had been shaken by their illness diagnosis. Sandra's experience is particularly reflective of the empowerment that was gained from doing research on and making decisions about medication for MS. She said:

*I did a lot of research, and I went through the library and I got journal articles. I really wanted to get a perspective of somebody who was using the drugs, that's what I wanted to know. I didn't, once I had done sort of the academic research to find out which is the most successful drug for my situation, I wanted to see how it affected people because overriding theme of all these drugs is that they can make you feel pretty rotten and they can take a while to get used to and you can feel, their favourite term is 'flu-like symptoms'... and, you know, there were support groups online of people who had horror stories and there were, you know, other people who've had no problems, and the long*



*and the short of it was I knew I was going to be injecting myself with something. The choice was 'Did I want to do it daily, weekly, or three times a week?' and so, at the end of all that, this is a couple months later, I decided to go with... three times a week.*

Here, Sandra makes evident the process that she went through in order to make an informed decision regarding her treatment, and how she sought to play an active role in managing her illness and maximizing her quality of life. The empowerment yielded through her involvement in making decisions about treatment reflects the proposition that “a belief in personal agency aids in coping with a stressful situation” (Compas et al. 1991, cited in Kameny & Bearison 2002, p.149). Being well-informed regarding illness and its treatment also appeared beneficial to coping for Aurelie, who appreciated health care providers’ explanations of how treatment and equipment worked. Thus, these participants found information about illness and its treatment beneficial to their coping process.

Laura was another participant who put a great deal of effort into researching breast cancer and its treatment. However, Laura had difficulty processing the information gathered shortly after her diagnosis, which she remembered by saying:

*Initially I was, I wanted to read and sort of find out, but I couldn't do it after I tried reading a couple of things because um I, I came across something that was like Stage I breast cancer, you know, this mortality, uh, rate and Stage II was, and I was like 'Oh I can't deal with that right now.'*

Here, Laura described her reaction to information about prognoses for different stages of breast cancer, which was emotionally challenging to deal with early in the illness experience. This comment offers insight into the complexity of negotiating information regarding illness for those newly diagnosed, especially because some types of information, such as mortality rates or long term limitations, may be particularly hard to process early in the illness experience before coping strategies have been developed.



Elizabeth, who also communicated feeling overwhelmed by information, photographed the substantial amount of information that she acquired after being diagnosed with depression.

She explained:

*This is a mass of information that I acquired from, oh boy, uh, some of those were medical sheets. Some probably would have been from like four or five different sources at least plus medical sheets so that was kind of the information I was getting from different sources and it was overwhelming... This sheet on top was in particular the best because it was the most practical whereas a lot of them were more kind of like your text book analysis. That one was like, I mean it talked about, you know, what TV shows to watch or to avoid and it talked about um just to not expect people to understand you right now, to have people to help you make meals, help, you know.*



She elaborated on her feelings of being overwhelmed with information, saying: *It really seemed like a lot of discrepancy amongst people, you know, about what ought to be done [to treat depression] and, and so then there was just me experiencing it all.* In making this comment, Elizabeth offers insight into her struggle to negotiate the different information and opinions



about treatment that she was receiving. Although Elizabeth chose to shoot this photograph in black and white, her words emphasize that managing depression was not ‘black and white’ because of the multitude of and inconsistency in the information that she received. Thus, Laura and Elizabeth communicated that too much, contradictory, or negative information may be problematic for individuals newly diagnosed with illness. This may especially be the case for young adults who have little prior experience with chronic or life-threatening illnesses (Politi et al. 2007).

However, later in the illness experience, Laura began to do extensive research on breast cancer and its treatment. Thus, doing research became a major part of her everyday life. In order to highlight this, Laura took a photograph of some of the articles that she had recently read:



*I have piles of information on breast cancer, period. But I have like a folder on breast reconstruction, um, so yeah, just that's kind of a reality for me right now, and like this one, this pamphlet you can't really see but it's from a surgeon in Seattle, Washington 'cause I have family there so I could potentially go there... and this article is called the*



*ABC's of Breast Diseases and Breast Reconstruction after Surgery and I have, yeah, tons of articles on different stuff, different options.*

Throughout Laura's interviews, it became evident that gathering information and knowledge about breast cancer was an important way for Laura to cope with the illness because it provided an active way for her to manage the physical and psychosocial implications, similar to what has been reported in existing research on young adults with cancer (Kyngas et al. 2000; Miedema et al. 2007). Thus, similar to Sandra, gathering information was a key source of agency during the illness experience.

Finally, some of the participants discussed the need for further information related to illness. While Nicole felt that information existed for newly diagnosed individuals, she had not encountered information about what to expect in regards to a future with epilepsy. When asked if she believed that she could access such information, she replied:

*Well, I think I'll have some problems probably finding it. I don't feel like epilepsy's very well talked about, you know, like cancer, you can find information anywhere on that. I don't feel like it's maybe a well known disease, like people know about it and they, they know the stereotypes but I don't think information would be, [that] I'd be able to find it. I think it would be a little bit hard at the beginning. I'd have to do some searching, um, so with Saskatoon being a smaller city too, I think it's probably harder to access the stuff that you could probably get in it in Vancouver or Toronto.*

As such, Nicole was uncertain of the long-term implications of the anti-seizure medication that she was taking, specifically with respect to becoming pregnant in the future. Nicole also emphasized a need for greater awareness and understanding of epilepsy, as she perceived the omnipresence of cancer to overshadow other illnesses in today's society. However, Laura also indicated the need for increased research and dissemination of research findings related to pregnancy and fertility for women affected by breast cancer, a finding noted in existing research on young women affected by cancer (Coyne & Borbasi 2006-7; Dunn & Steginga 2000; Grinyer 2007; Odo & Potter 2009). Further, like Nicole, she proposed that differential access to



information and services exists among different parts of Canada. Therefore, these participants, as well as Sandra and Nancy, expressed that their informational needs related to pregnancy and fertility with respect to serious illness had gone unfulfilled.

While Laura and Nicole both focused on the need for greater information about fertility and pregnancy in relation to their respective illnesses, other participants suggested a need for the availability of information more generally. For example, Aurelie felt that research about individuals affected by brain tumours was lacking. Nancy echoed this sentiment but in respect to endometriosis because of the uncertainty that surrounds its diagnosis and treatment. Specifically, she questioned why none of the treatments that she had been prescribed were specific to the illness, noting that her medications were typically used for birth control and haemophilia. Despite being adamant that more research and greater awareness would benefit affected individuals, Nancy felt that this was unlikely because of the stigma surrounding gynaecologic health, an issue that has been highlighted in existing research on women with endometriosis (Seear 2009b).

Leanne shared some of Nancy's concerns regarding information about and the treatment of the illness by which she was affected. She stated on a number of occasions that the health care providers with whom she was in contact did not seem to have an adequate understanding of anorexia or how it should be treated. Leanne cited several examples of unhelpful advice and negative interactions with health care providers that emphasized their lack of understanding of anorexia and its treatment. Leanne summed up her feelings by saying: *My experience has shown me that people don't know what they're talking about when it comes to eating disorders. They know the physical, they don't know anything else. They don't understand what it's like.* As such, Leanne felt that there was a need for greater awareness of eating disorders and their treatment,



while also recognizing that experiences of disordered eating may differ. Increasing awareness was particularly important to Leanne because that could assist family members, friends and health care providers in helping those suffering from eating disorders and combat the multitude of websites that facilitate disordered eating. The comments made by Leanne, Nancy and Aurelie point to specific suggestions for further research, in addition to the gaps in knowledge identified by other participants, emphasize that information can be beneficial to individuals who are trying to make sense of illness, as well as health care providers and others with whom ill individuals interact.

The above paragraphs describe participants' experiences related to the acquisition of information, its adequacy and unfulfilled informational needs. Their comments highlight a number of issues related to gathering information about illness and its role in coping with illness. First of all, it is evident that acquiring information about illness was typically beneficial to participants, as it gave them a better understanding of the physiological experience of illness and offered an active way of coping. However, two participants noted that certain information was overwhelming at times, particularly when newly diagnosed. Further, despite accessing information from a variety of sources, several participants talked about the value of practical advice from others with similar experiences. Finally, participants identified informational needs that had gone unmet, including the need for general information about certain types of illness and specific information about the impact of illness and treatment on fertility and pregnancy.

#### *5.2.4 Summary*

In this theme, discerning and learning about illness, I delineate the process that participants went through in recognizing initial symptoms and signs of illness, receiving or



obtaining a diagnosis, and gathering information about illness. In the first sub-theme, I identify how participants experienced an out-of-the-ordinary bodily state which led them to consider possible explanations for what was going on. In doing so, many participants drew upon typifications (Bentz & Shapiro 1998, p.50, cited in Bentz & Rehorick 2008, p.17-18), or existing meaning structures, in order to make sense of their unfamiliar bodily state. Typically, the typifications drawn upon associated symptoms or signs of illness with insignificant or more common place health problems. Some participants also used “effortful possibilizing” (Zaner 1989, cited in Rehorick 1986) through their consideration of unknown experiences as possibilities for what they were experiencing. For two of the participants, the experience of an acute episode resulting from illness, a seizure, negated the possibility of trying to understand their bodily state at the time, although reflection occurred after such an occurrence. Thus, this first theme highlights how participants sought to make sense of the unfamiliar state of their bodies that resulted from the onset of illness.

The second sub-theme focuses on the process by which participants obtained or received a diagnosis from health care providers. While there was variation in the way diagnosis came about, some of the participants shared similar experiences of learning about their illness. Interestingly, some of the participants’ diagnoses would not likely have occurred had they not been in contact with the health care system for a routine appointment or regarding another health issue. Further, some participants went undiagnosed for some time following their initial consultation with a health care provider, partly because some health care providers believed that certain participants were too young to be affected by a serious illness. Thus, these participants’ experiences resonate with existing literature that suggests that both young adults and health care providers’ perceptions contribute to the characterization of young adults as invincible and having



good health, which can lead to delays in diagnosis (e.g., Albritton & Bleyer 2003; Miedema et al. 2006). This finding indicates a need for greater awareness of the prevalence of serious illness in young adults in order to challenge stereotypes related to serious illness and educate young people about symptoms and signs and the health care system.

Participants' discussions of receiving or obtaining a diagnosis also raise issues related to coping; specifically, how participants learned about their diagnosis or the possibility of illness appeared to influence how they managed such news. Those participants who acknowledged or were told of the possibility of serious illness seemed to cope better with diagnosis because they had time to initiate coping mechanisms. For example, Stacey's realistic approach to the possibility of having a serious illness enabled her to prepare herself for such a diagnosis so when it was confirmed she was quick to tell others and open pathways of support. Sandra's comments also support this idea: although she and her mother were shocked at the possibility that she was seriously ill, being aware of possible diagnoses allowed her and loved ones to do research and compare her symptoms with those of specific illnesses. Thus, when her diagnosis was confirmed, she was already aware that MS was the likely diagnosis. Although these two young women had different experiences of obtaining an illness diagnosis, their stories highlight how awareness of possible illness diagnoses allowed them to begin to cope with the possibility of illness and implement coping strategies such as seeking information and initiating social support. This finding is similar to existing research that found that a realistic yet optimistic outlook regarding cancer prognosis was associated with better psychological adjustment (Classen et al. 1996, cited in Miedema et al. 2007, p.42). However, it is necessary to note that these two young women were approximately 30 and 33 years old respectively when initially diagnosed, and may have



therefore reacted differently to such openness in the diagnosis process than other participants who were younger at the time of diagnosis.

Above all, the participants drew attention to the importance of supportive interactions with health care providers during the diagnosis process. For some, health care providers readily offered information about and explanations of illness. Others, however, reported feeling as if health care providers did not: take them seriously, validate their symptoms, or offer adequate information or support. As such, participants struggled with how to make sense of their diagnosis, recommended treatments, or future with illness. Two participants, Nancy and Melissa, were particularly frustrated with certain encounters with health care providers, and therefore had trouble accepting their diagnosis or prescribed treatment. In Melissa's case, numerous health care appointments yielded no definitive diagnosis and led her to consult with alternative health care providers who then diagnosed her with two forms of illness. Melissa expressed relief over these diagnoses because that provided a direction for treatment. This sentiment was shared by other participants, such as Elizabeth and Melanie, who emphasized that a diagnosis would initiate treatment and restore their health so that they could continue on with life.

Finally, participants' comments about gathering information about illness demonstrate the significant role that information played in the coping process, as has been reported elsewhere (e.g., McCaughan & McKenna 2007; van der Molen 1999). Information was particularly important to some participants because it offered them an active way to cope, as well as agency through the involvement in making decisions about treatment. Participants also perceived information provided by health care providers as a sign of support, and participants who did not receive such information initially struggled to understand their diagnosis, including Nicole, Nancy and Elizabeth. On the other hand, Laura and Elizabeth found certain information and



discrepancies in information hard to deal with. However, most participants reported that they received informational support from other sources when certain health care providers were not helpful in this way. While the majority of participants' informational needs were met, some participants advocated for more research on certain types of and specific issues related to illness. Therefore, participants' experiences reveal the importance of gathering information to the coping process, although it may be necessary to negotiate what type of information is acquired.

Overall, this broad theme highlights the discernment of the onset of illness by participants and/or health care providers, and the learning about illness that resulted from diagnosis and gathering information. Specifically, I have sought to highlight how participants entered an unfamiliar world as a result of their bodily experiences and diagnoses that included learning about illness, treatment and/or medications. Further, participants' experiences illuminate how they understood their lived bodies (van Manen 1990) by engaging with: their own existing knowledge about illness, other individuals including health care providers, and information about illness gained from a number of sources. Thus, participants' subjective experiences occurred and were made sense of within their social context, showing one way in which illness can be considered a socially-mediated experience. In the following theme, I further this point through the examination of how the onset, diagnosis, and treatment of illness led to disruptions and limitations in participants' everyday lives, some of which were short term and others that had long term implications.

### **5.3 Illness and Treatment as Disruptive to Everyday Life and the Lived Body**

This theme focuses on the disruptions and limitations that the young women experienced in their everyday lives because of treatment and the physical side effects of illness. I identified



four sub-themes related to the broader theme, which reflect issues associated with: disruptions caused by treatment, the integration of medication into everyday routines, limitations caused by illness, and the management of physical changes and the relationship with the body. The four sub-themes discussed in this section highlight the impact of illness and its treatment on participants' physical selves, as well as their everyday activities. As such, this theme demonstrates how the physical and medical experience of illness affected the young women's psychological and social well-being through the disruptions and limitations that illness introduced. While the participants each had a unique experience of illness with respect to treatment and its physical implications, their stories reveal a common experience of illness as disruptive and bringing about limitations in their everyday lives.

#### *5.3.1 Treatment as Disruptive to Everyday Life*

Five of the participants in the study (Aurelie, Stacey, Leanne, Laura, and Melanie) discussed the disruption that receiving treatment for illness caused to their lives, although the extent of the disruption varied. In particular, these young women all went through a period of treatment that included: surgery, hospitalization, and/or intensive treatments. During this time, they were required to negotiate the physical side effects of treatment and their impact on everyday life. Further, these young women experienced disruptions in their social roles related to employment, education, leisure, and/or family.

For example, Aurelie underwent surgery in December, followed by subsequent months of treatment, which she recalled by saying:

*I had some therapy, physiotherapy in January and... After, ah, February and early March, it was radiation and, ah, ah, from April to September, it was chemo. And, um,*



*that's it. Um, now it is stable. So... for me, I was sick, ah, at the end of chemo because I took a [type of chemo]), it's 5 days per month... So it's, uh, 6 or 7 pills that you take at bedtime and it's horrible to take those pills - before, it's okay but after, it's horrible - the taste - and you know that you will be sick, uh, the day after. So, yeah, but after 1 week - because it's only 5 days, but for me it takes 1 week to recover, after you, you are all good, like usually.*

Thus, Aurelie's schedule during this time revolved around treatment appointments and recovery. As a result, Aurelie took six full months off from her education and went part time for another couple of months before returning full time to university. Furthermore, she also indicated that she did not partake in her usual social activities either during the treatment period, such as going to the movies or socializing with friends.

Stacey was another participant who reported having to manage the disruption of treatment to her life and re-organize her schedule for treatment. As discussed in Chapter Four, Stacey's first diagnosis occurred at a pivotal time in her career, as she had just begun her first management position. She emphasized the immense disruption that her diagnosis brought about in her everyday life, as treatment and the side effects would prohibit her from fulfilling her responsibilities at work. She communicated that the notion of working part time or not at all was appalling to her, and she continues to struggle with this issue. Stacey described feeling as if she had to *press pause* on life because of illness, and talked about her recent decision:

*It's something that took three times in eight years for me to go 'If [the doctors] call and I'm not available, I'll get back to them or they'll get back to me and it'll be okay.' And nobody got mad at me. I think I was always worried that the doctor was gonna get mad at me if they called and said 'But we booked you here.' and it was like 'Oh my gosh, well we bought plane tickets.' That they would say 'Well that's it, I'm not gonna be your doctor anymore.' So, I don't know what I thought would happen, I don't know what would happen, it hasn't happened yet, but nothing's fallen apart and everything's been okay.*

In addition, managing treatment appointments was especially complicated for Stacey because she lives in a rural community that requires her to travel to the city. Thus, Stacey's comments



demonstrate her efforts to move beyond the disruption that treatment for breast cancer has caused in her life, which resulted in her putting much of her life on hold for several years,

Leanne also found her life greatly disrupted by treatment for anorexia. Specifically, she was hospitalized for three months, during which time she received medical and psychiatric care, as well as rehabilitation. Leanne described the impact that this had on her life:

*It really sucked. Like, I had no concept of days of the week, of time, of, um, hours, you know, minutes felt like hours. Hours felt like days. I'd go to sleep and I'd wake up and I would think it was seven in the morning and it'd be like two in the morning kind of thing. So it sucked. Like everyone else was kind of, you know, going on, living their life. Like, my mom came and visited me every day so I would ask her to bring the newspaper and read me what's going on... But to me it feels like, for the vast majority of last year or so, I would say a good six months, like I lost them.*

Here, Leanne intimated two distinct implications that her hospitalization had: first, it affected the way that she thought about time, or her time perspective (Charmaz 1991), and second, it caused an interruption to her everyday life and biography (Bury 1982). In respect to the first, Leanne indicated that her sense of time became confused and time seemed to drag on, suggesting the monotony of life in the hospital. Leanne's description of time during her hospitalization calls attention to her lived experience of time, in that her time perspective shifted away from 'clock' time to one that was uniquely hers (van Manen 1990). Her comments echo what has been reported in other research on serious and chronic illness, in which ill individuals communicate a subjective experience of time and a departure from the "common time perspective" shared with others (Charmaz 1991; Good 1994). Thus, visits from her mother and other family members were important to her maintaining a connection to the passage of 'clock' time.

Further, Leanne's comments highlight the disruption to her everyday life and biography arising from hospitalization. In particular, she referred to her hospitalization and recovery as *lost* time because she was removed from her everyday roles and responsibilities, as well as the usual



contact with family and peers. Thus, Leanne experienced hospitalization due to illness as an interruption (Charmaz 1991), as well as a disruption to her biography (Bury 1982) that cannot be ameliorated. One impact of this interruption that Leanne reported was that she was unable to continue her education during that time, and therefore she would take longer than previously expected to complete her Master's degree. Additionally, Leanne also experienced disruptions to her relationships because she was unable to communicate and socialize with others as she had in the past. Leanne's relative isolation from others during her hospitalization was difficult for her partly because the maintenance of friendships can be particularly significant for young adults experiencing a serious illness in that they allow young adults to maintain contact with their peer group and issues associated with their developmental stage (Lynam 1995), which may help them to feel a greater sense of normalcy.

While Laura was able to maintain many of her usual roles during treatment, she was still required to negotiate the physical side effects and their impact on everyday life. She indicated that she experienced nausea at some points during chemotherapy, as well as difficulty sleeping because of one of the medications that she was taking. She indicated that having breast cancer was a *setback* in that it disrupted the achievement of certain goals:

*It took me longer to finish my Masters... and like a year ago I didn't get a job because I still had so much left of my Masters, I had a class to take and I couldn't do the hours and I was like, it was a big deal, I almost quit my Masters because I really wanted that job so much... The job is going to be posted again but I still might not get it because now I don't have enough seniority to get it.*

Laura indicated that, although she was able to continue with school and is employed in her field of expertise, having breast cancer resulted in an interruption to her studies which has affected her employment opportunities. She continued on to talk about how taking time off work for treatment was also difficult because she was required to re-familiarize herself with her job after



being away and was only starting to feel settled again more than a year later. Thus, despite maintaining many of her roles during treatment, Laura experienced illness as an interruption similar to what was described by Leanne.

Melanie also experienced disruptions following the mastectomy and reconstruction process, although she was able to manage through the support of her family members. Foremost, Melanie's diagnosis occurred at an important time in her life, when her daughter who had been born prematurely was due to come home from the hospital. As a result, Melanie had to negotiate care for her daughter and son while she underwent and recovered from surgery. In respect to this photograph, she said:

*This one is of [my son]. It would have been a couple days after I had my biopsy done and it just shows how young and little he looks and... At least with [my daughter], I could still hold her and feed her and everything because she was under ten pounds. So I could still do a whole lot of stuff with her, it's just I'd just get tired really quick, is the biggest thing. So most of the time they'd come and lay with me and that kind of stuff.*



In sharing this photograph, Melanie highlighted the challenges that she faced caring for her children after surgery. As such, she sought ways to adapt to the side effects of her treatment in order to perform her role as a mother.



The above quotations describe how these five young women experienced treatment for their illness and its side effects as a disruption to their roles, responsibilities, and everyday lives. Their stories demonstrate how treatment was not viewed with respect to its purpose or the positive benefits that it yielded, but instead in relation to the impact that it had on their lives at the time or since then. In particular, for these young women, treatment was often disruptive to physical well being, and the ability to fulfill roles and responsibilities related to education, employment and/or family. Additionally, some of these participants indicated that they were unable to participate in leisure activities or social events that they would have in the past, thus leading them to feel as if they were missing out on life. The need to negotiate disruptions to roles and responsibilities has been identified in research on young adults with cancer (Grinyer 2007; Odo & Potter 2009) and mothers with cancer (Fitch, Bunston & Elliot 1999), although it has also been suggested that young people may seek to maintain their past roles in order to cope with illness (Kyngas et al. 2001). For example, Laura and Melanie sought to continue various roles during treatment or following surgery, despite that the side effects of this treatment made it challenging to do so. The experiences of these participants, especially evident in Stacey's comments on not wanting to put life on hold for treatment any longer, speak to the desire to continue with past roles and responsibilities; however, their stories also demonstrate the challenge that this may pose, as it may be difficult to maintain a sense of normalcy when everyday routines become focused on medical appointments and the management of side effects.



### 5.3.2 Incorporating Medication into Everyday Routines

Other participants also experienced an initial disruption to their lives because of illness, such as Nicole who was hospitalized for three days following a seizure, or Sandra who had to adjust her daily activities and plans during steroid treatment for the ‘episodes’ of MS that she experienced. However, following such events, these participants’ treatment plans did not involve intensive therapy or hospitalization. Instead, they were faced with the challenge of incorporating medication regimens and advice from health care providers into their past routines. Additionally, Nancy and Melissa shared similar experiences of trying to negotiate how to best manage the treatment of their symptoms and continue to fulfill their roles and responsibilities.

As reported earlier, Sandra was active in determining the course of her treatment regimen for MS and made her decision based on trying to minimize the side effects of the medication and the disruption to her everyday life. Specifically, she chose to inject the medication three times a week so that the potential side effects would be less than if she took the medication once a week, but also so that she would not have to endure the disruption of injecting herself daily. Sandra expressed annoyance at having to follow this medication regimen and reported experiencing side effects from the medication, such as achiness and chills, which could disrupt her sleep and other daily activities. In order to illustrate the impact on her life, Sandra talked about this photograph:

*So this is my medication, I keep it in the fridge. That’s the box that it comes in, and then that’s the syringe with it in a package... It’s so much part of my life, the actual medication, that I thought for sure that it needs to be part of this. It’s tucked away [in the fridge], but I know where it is always, and it is something that I have to be conscious of because as it starts to run out, I have to re-order it and then I have to make sure I go pick it up and do all that kind of stuff. So yeah, it’s important to have and to keep in mind, and I can’t inject it cold from the fridge so I have to go through the whole process, the whole ritual of that on Monday, Wednesday and Friday.*





Thus, Sandra emphasized the need to constantly be aware of her medication schedule and supply, as well as her resentment of this additional concern in her life.

Nicole was another participant who talked about the impact of her anti-seizure medication on her everyday life and shared many of Sandra's frustrations. In respect to this photograph, Nicole stated:



*So I just took a picture of the pills that I have to take every day. Um, I take them twice a day and that's a one month supply so it looks like a lot but it goes really quickly. Um,*



*yeah, I, I hate taking them 'cause they make me so sick, um, plus they look so little, like how could something so little really make me that sick or really change anything so. I just decided to take a picture of them to kind of show that, kind of show what I do take on a daily basis.*

Nicole indicated that she resented having to remember to take her medication, as well as the side effects that it causes. She also described her medication as a *hassle*, emphasizing that she looked forward to the day that she would not have to take it anymore, although she was unsure of when that would be. Thus, like Sandra, Nicole was unhappy about having to incorporate medication and its side effects into her daily routine because it threatened her freedom to do what she wishes and exert control over her life. Existing research on young adults with chronic illness suggests that such resentment of medication regimens can be concerning, as some members of this population may not comply with treatment because they dislike taking medication or do not want treatment to control their lives (Rosina et al. 2003). However, these two participants currently reported adhering to treatment.

Nancy also commented on the disruption that she experienced having to incorporate medication into her daily routine because of endometriosis. Foremost, she discussed her difficulty in making decisions regarding when to take certain medication:

*I'm not supposed to take [the blood clotting pills] every day and honestly I couldn't afford to take them every day. I'm only supposed to take them on the days that I'm having the heaviest bleeding. So the gynecologist explained to me, she said 'When you wake up in the morning, like you have to decide "Okay, is this what I would consider the heaviest day? Or a heavy day?" And then from there, take the pills or not take the pills.' I was like 'Well, what if I don't start like bleeding right away in the morning? 'Cause a lot of times I'm not waking up first thing to this.' ...So it's kind of been really tricky... [and] I don't want to be carrying all those pills around with me, like jingling in my purse all day when I'm trying to go to work and stuff.*

Here, Nancy explicated the decision making process that she goes through each day, which she found confusing and time consuming. In addition, if she decides that her symptoms warrant



taking the medication, she must remember to do so throughout the day as she tries to keep up with her everyday responsibilities, including university classes and multiple part time jobs.

In order to illustrate her experience of taking medication and vitamins to manage endometriosis and its symptoms, Nancy took two photographs that show the variation in her day-to-day life:

*Okay, so that's the number of pills that I take on a good day, just the three multi-vitamins... And just to kind of give you a contrast of that, a good day versus a bad day, how many pills that I take... But those are the hemophiliac pills, the blood clotting pills is what they are... So yeah! That's my little pile of pills. And, ah, yeah, and then these ones are the ones that I take for pain. And I didn't want to...like I do take a tiny little hormone tablet but I didn't want to take it out of the package 'cause I knew I would totally lose it. But that's added into my little cocktail. Yeah, so that's what's up!*



This quotation and two photographs allowed Nancy to sum up a good day as one in which she only takes vitamins, and a bad day as one that involves numerous pills for blood clotting and pain in addition to the vitamins and a birth control pill. Her explanation of the photographs highlights the variance that she experiences with respect to medication on a day-to-day basis, which she has struggled to cope with. Particularly, Nancy complained that it was difficult to prepare food to take with certain medications given the pain that she often experiences and her busy schedule. In making these comments, Nancy highlighted the belief that the trouble involved in taking her medication typically does not outweigh the benefit that is gained from it, as she said



the medications are not always effective in alleviating her symptoms. Therefore, these examples demonstrate how Nancy struggled with the management of the symptoms of illness and the incorporation of different medications into her everyday life.

Melissa described a similar experience as Nancy with respect to incorporating the treatment program into her everyday life. However, having received diagnoses of hypoadrenalism and hypothyroidism from an alternative health specialist and a naturopathic doctor, Melissa's treatment involved vitamins and changes in diet rather than prescription medications. She talked about how complicated the treatment program was:

*The program I went on with [the alternative health specialist], um, I'm not allowed to eat any dairy, starches, sugars, um, and so that really limits the amount of food you can eat ...it's really strict. Ah, the program regarding diet from the other, uh, from the actual naturopath, she thought that was a great idea for me to stick to but she also wanted me on gluten-free products. And I was like 'I don't know what I can eat if you also add in gluten-free products on there too... So yeah, I try and follow it as best as I can, but especially in a lifestyle that I'm in with going to university, it can't happen all the time. It's just, it's impossible. But I do the best I can to incorporate, you know, whatever I can of both and take as much of their remedies or herbs or whatever I can.*

In addition to changes in diet, Melissa incorporates certain vitamins into her daily routine in order to support the functioning of her adrenal glands and thyroid, and overall well-being. However, she noted the challenge that she faces in attempting to incorporate these programs into her life while attending university, having to make compromises due to time constraints.

Finally, Aurelie also discussed how she has incorporated medication into her daily routine, along with ongoing appointments with health care providers to monitor her for further signs of a brain tumour. Despite the disruption, Aurelie described how managing illness in everyday life is something that she has come to accept:

*So, [this is] all my medication, um, that I will have all my life, uh, all the rest of my life, dealing with doctors, hospital, medication, dealing with that and, uh, uh, before the*



*hospital frightened me a bit - hospitals in general - and, I, um, went to the doctor just if I was really obligated or, and, um, now, um, that I know more of the hospitals in general, and doctors and nurses, um, (inaudible) um, I like quite being in the hospital, I feel like 'Oh! Oh, yah, it's great!' So when I go to, to the [hospital], I just, it's just a pleasure to, to find again a place which you know or, I don't know, I'm not so afraid and... no, I'm not afraid at all.*



Thus, Aurelie regarded the changes to her life resulting from illness in a positive way, despite causing many disruptions to her life. These comments reflect her appreciation for the health care providers and medical treatment that had likely saved her life, as well as her optimistic nature.

The above paragraphs outline how some of the participants were required to incorporate medication and other forms of treatment into their daily routines. For Sandra and Nicole, this meant taking medication and negotiating the side effects in respect to their roles and responsibilities. Nancy had a similar experience, although she was required to make decisions about taking medication on a daily basis which she found challenging. Nancy also identified the need to adjust other aspects of her life in order to accommodate the requirements of her medication. Melissa had a similar experience, finding it difficult to reconcile a strict diet with her busy university lifestyle. While these four participants focused on the negative aspects of the incorporation of medication and other treatments into daily routines, Aurelie described this in



positive terms, perhaps reflecting her faith in medicine and its success in treating the brain tumour by which she was affected. Participants' comments about the resentment of having to incorporate medication regimens into everyday life call attention to the need for support in this area, as young adults who do not successfully adjust their daily routine to include medication may fail to adhere to treatment. Such an issue has been reported elsewhere (e.g., Badlan 2006; Rosina et al. 2003), and may contribute to negative health outcomes.

Interestingly, five participants out of the nine who completed the photovoice project chose to photograph their medication, and some included more than one photograph. The abundance of such photographs is likely because medications offered a concrete and simple object to photograph (easy to access and understand). As well, medications were a specific example of how their lives had been changed by illness (incorporating medication into daily routines). However, participants may have had additional, more personal reasons for photographing medications. Nancy, for example, used her photographs to illustrate the variation in her symptoms and the need to make decisions about medication daily. As well, the type of treatment prescribed by her health care providers was a source of tension for Nancy, and thus figured prominently in her illness experience and photographs. For Laura, a photograph of the medication that led her to experience chemically-induced menopause (not shown) illustrated her uncertainty as to whether she would be able to have children in the future, an issue that was prominent in her interviews. Thus, participants' photographs of medication reflect both aspects of their experiences that were simple to translate visually and were highly pertinent to the challenges that they were currently experiencing.



### 5.3.3 *Negotiating Limitations due to Illness and Treatment*

As a result of illness and its treatment, some of the participants experienced limitations that prohibited them from carrying out everyday tasks and leisure activities. The following paragraphs describe some of the restrictions that illness and its treatment have placed on what the young women were/are able to do. While some limitations that the young women experienced were temporary, others continued to deal with illness-related limitations on an ongoing basis. Some participants expressed frustration that their illness required them to exercise caution, adapt to limitations, or incorporate changes into their daily lives. Further, some limitations imposed by illness required the young women to re-negotiate their sense of identity, as the effects of illness prohibited activities or characteristics that formerly defined them, such as riding a horse or being independent.

For example, Aurelie acknowledged the significant impact that her illness had on her everyday life when she described its physical implications with respect to this photograph:





*I took a photo of the stairs because I take care more with stairs or getting on and off the bus, because I am always afraid of falling or that kind of thing... With a history of a brain tumour, I take huge precautions. [Climbing stairs] is a natural thing for the others, but for me, it's a tricky thing, you have to pay attention.*

In addition to exercising caution, Aurelie discussed how her decreased mobility affected other everyday activities such as handwriting or opening a door, which no longer come as natural movements. Further, she indicated that she tires easily and cannot drive, play sports, and dance or have a few social drinks with friends at the bar because of the effects of the brain tumour on her leg and the medication that she is required to take. Thus, Aurelie's experiences demonstrate how limitations imposed by her illness brought about changes to her everyday life and leisure activities. However, she noted that she is making an effort to do strength building exercises that would help to overcome some of these limitations.

Nicole also talked about the changes that she was required to make in her leisure activities because of restrictions introduced by epilepsy. Similar to Aurelie, Nicole reported that her social life had changed due to illness, because being around strobe lights could cause her to have another seizure, as quoted in Chapter Four. Although she previously went to the bar with friends only occasionally, Nicole felt that it was more difficult to spend time with some of her friends because of this restriction, which made her feel different from others her age (to be further discussed in Chapter Six). She also indicated that she exercises greater caution because of the possibility of having another seizure, which is of great concern to her family members. With respect to this photograph, she talked about the potential limitations that she faces:

*They did take my license for three months after... and then, um, up until October of this year I'm on a medical like extension kind of thing so every three months my doctor has to fill out a form saying I'm okay and this is what's been going on. Um, but they're a little like, just a little bit concern[ed], like I have my motorbike license and I ride a bike too, and that's where my parents were like 'No, you're not doing it anymore.' But it's, I know that I just have to be more careful. I, now that I've had a seizure, I kind of know like if*



*something's going to happen, I'll have a warning, I can pull over, I know something's going to happen. So everyone else is concerned about it and I'm like 'I know what, if something's going to happen then I'll have time. I'll have a least a minute so.' ...I'm a little bit concerned like to ride my bike and, and stuff like that, I'm a little bit worried about it but I don't want it to stop my life. I don't want it to affect my life anymore than it has.*



Thus, Nicole used this photograph to depict this ongoing source of tension between her and her family members; while her illness has not actually limited her ability to drive up to this point, it has caused concern and made this past time less enjoyable for Nicole. This quotation and photograph highlight the need for young adults to manage their relationships with respect to the implications of illness, which will be further discussed in the following chapter.

Stacey also talked about the impact of illness on everyday activities and leisure activities. For instance, she indicated that she has had to exercise caution when driving following surgery, as certain movements can aggravate the surgical site, although she felt that driving would not be a concern once the site had healed. However, Stacey also experienced long term limitations as a result of breast cancer surgery:

*I do have some limitations, um, and they're slowly becoming things that are going to permanently change some of the things that I'm able to do. Um, one of the things that can happen from breast cancer related surgery is something called lymphedema, which is, um, severed lymph vessels, um, cause the flow of lymph fluid to not be able to travel back*



*out of your extremities and so I have constant swelling in my right arm and I am desperately right handed, um, so my hand is always fat and tired and so it means that things like waterskiing and snowmobiling and canoeing are things that, I don't know if you shouldn't do, um, but yeah, probably textbook 'shouldn't do', because if you read the textbook on it, you should never lift anything, carry anything, do anything and I'm like 'Who the heck are those rules supposed to be for? 'Cause who doesn't have to carry their groceries, you know what I mean? Life just doesn't work like that. Um, what if you had a child? How do you not lift the baby?' ...I guess it's not supposed to be the end of the world but it's hard admitting that you can't do things when before your body would have and would have done them forever.*

She also discussed adaptations that she has made in order to continue some leisure activities. For instance, in order to participate in a snowmobile relay to fundraise for breast cancer research, she adjusted the type of throttle on the snowmobile so that she could use either hand to control it, and wore a compression sleeve and glove. However, Stacey communicated that she dislikes wearing compression garments and has not found any that adequately manage the symptoms of lymphedema.

Some participants also talked about limitations that were more transient than those discussed by Stacey, Aurelie and Nicole. For example, Elizabeth experienced both physical and psychological limitations in her everyday life because of depression, specifically with respect to her behaviour, energy level, and mental functioning. Elizabeth shared this photograph as an example of her altered behaviour and mindset during that time, which she explained by saying:





*This is the key image, um, 'cause this is very much what it was like - to come home and crawl in and roll up in bed... [to] not want to go out and, and - isolation... There's other things maybe that would have normally been a priority and at that point I just was alone with my thoughts and just wanting to be alone with my thoughts, curled up in bed.*

Thus, Elizabeth communicated that the symptoms of depression that she experienced included wanting to isolate herself during that time, which resulted in her not participating in activities that had formerly been a priority. Further, Elizabeth discussed how the lack of energy and inability to concentrate resulting from depression limited the fulfillment of certain responsibilities related to her education and home life. For instance, she reported having difficulty completing assignments for university classes and her share of the household chores.

Melissa also experienced a number of symptoms that were no longer present at the time of her interview. As discussed previously, two of such symptoms were dizziness and debilitating pain in one foot which led her to temporarily use a wheelchair to go between classes at university. In addition to causing problems with walking, these symptoms limited a number of her everyday and leisure activities:

*There's a lot of things that I thought I'd never be able to do again.... with my foot, I wasn't able to drive. I lost all my independence because it was my right foot, so I wasn't able to drive. What I consider to be my normal activities, I had to stop, because I could no longer ride horses ever since.*

In saying this, Melissa highlighted her past belief that she would never resume her past activities because of the effects of illness. In addition, she noted that her independence was threatened by the limitations imposed by illness, as she relied heavily on her younger sister with whom she lived to drive her places and to take care of the housework, which was problematic for her sense of well being and relationship with her sister. Luckily for Melissa, the pain in her foot has improved more recently due to the recovery program that she was placed on by an alternative health specialist.



Leanne also shared her thoughts regarding the loss of independence that accompanied the illness-related limitations that she experienced. Foremost, Leanne reported that she was so weak when admitted to the hospital that she could barely move on her own. As such, she had to rely on health care providers for assistance:

*I couldn't do anything for myself. Like, I could move my arms and I could kind of move my head and I could kind of move my upper body but I couldn't really move around, like I couldn't get up out of the bed. I was pretty dependent. And for me that was terrible because I've always been an independent person so to have to rely on everybody for my most basic needs, it was terrible. Like, it was hard for me.*

Although she slowly recovered physically and mentally, Leanne continued to experience limitations while in the hospital and following her release. She recalled in relation to this photograph:



*When I was in the hospital and for pretty much all of last year, and a little bit of this year, I wasn't driving. I couldn't drive. I wasn't strong enough to drive. I had no freedom. I had to rely on, like, my mom taking me somewhere or my brother taking me somewhere. I couldn't just kind of pick up and go... I just couldn't do what I wanted. Even when I started working again in the school system in January and February, I had to get rides because I wasn't driving yet.*

Leanne emphasized how not being able to drive required her to rely on others on a day-to-day basis and contributed to her feelings of dependency. Thus, Leanne's comments highlight an



important issue: illness-imposed limitations may not only disrupt young people's everyday routines, but also threaten their independence, which may be newly established (Kyngas et al. 2001). The issue of independence is prominent in existing research on young adults with cancer, as the limitations imposed by illness are problematic because they contribute to a "retrograde step" in which young adults feel as if they are moving backward in their life course instead of forward (Grinyer 2007, p.74).

As a whole, this sub-theme identifies the significant effects that illness-related limitations had on some participants. Whether disruption to everyday life occurs on an ongoing basis or is only temporary, limitations that prohibited the young women from carrying out their usual activities were challenging to reconcile with their roles and identities as a young and able person, as demonstrated by comments from Aurelie, Nicole, Elizabeth and Melissa. In addition, other limitations associated with illness disrupted some young women's ability to do what others their age do, as Nicole and Aurelie no longer felt that they could socialize with friends as they had done in the past. As a result, the participants sought to adapt to limitations or find alternative activities that they could enjoy, as Stacey reported. Further, the comments of Leanne and Melissa suggested that it was challenging to manage limitations when they resulted in having to rely on others because they were formerly unaccustomed to being dependent on others. Thus, changes in abilities and activities because of illness were viewed as being detrimental to psychosocial well being and self identity, particularly because limitations were contradictory to the freedom and independence often associated with young adulthood. As a whole, these participants' stories demonstrate how limitations stemming from illness can bring about disruptions in identity, independence, and social relationships.



#### *5.3.4 Managing Physical Changes and the Relationship with the Body*

In this sub-theme, I explore participants' embodied experiences of illness through a focus on the need to manage an altered body and relationship with the body. In doing so, I highlight issues related to appearance, body image, and trust in and control over the body that some participants faced. These issues were experienced in the context of socio-cultural beliefs about age and gender, demonstrating how physical aspects of illness had psychosocial implications. I have divided this theme into two sub-themes in order to highlight how participants' relationships with their bodies changed even when the body was not physically altered by illness.

##### 5.3.4.1 Adapting to an Altered Body

Many of the participants talked extensively about the changes that they experienced because of illness with respect to their bodies. Specifically, some participants were physically changed by surgery and/or treatment and therefore were required to negotiate an altered body, as was the case for the young women affected by cancer. The young women's discussions of the physical changes that they experienced call attention to issues related to body image and appearance that allude to socio-cultural ideals related to youth and femininity. Thus, in highlighting these participants' understandings of the embodied changes that they experienced, this sub-theme calls attention to the convergence of the physical and the social; specifically, their stories of illness demonstrate how physical changes affected these participants' identities as young adults and women.

Laura was one participant who seemed preoccupied with the bodily changes that she endured, perhaps because she was in the process of making decisions about breast reconstruction



surgery. She reported a number of lasting changes in her appearance resulting from breast cancer surgery and treatment. Despite being an avid runner and exerciser, Laura indicated that she was unable to lose body fat, which she felt was *like it's stuck*. In addition, Laura discussed what it was like to have had a mastectomy:



*I kind of think sometimes that it's like 'Well, I'm like a boy or... like, you know, an eight-year-old girl on this side', 'cause it's completely flat. And then over here it's like, kind of like the old me and, you know, regular. And it's confusing, it's very confusing but, um, yeah, even like my right breast, I don't feel the same way about it as I did and it doesn't excite me, you know, and in terms of foreplay and stuff like that like it used to. It's kind of, I'm trying to, I don't know, stay detached from it in case I lose it, or I don't know what it is exactly but I just, and maybe it's just a reminder of like the huge tumour that grew in other one and it's like I don't trust breasts.*

This quotation elucidates the psychosocial impact of losing a breast and the perceived division between the two sides of her body, the old and the new. Laura emphasized that it was hard for her to comprehend that her physical form had been noticeably and permanently altered.

Additionally, she expressed feelings of distance and distrust towards the remaining breast, which she no longer views as having a role in her sexual relations and reminds her of the possibility of a breast cancer recurrence.



Melanie also discussed the physical changes resulting from breast cancer surgery, as she too had had a mastectomy:

*It was really ugly having that huge scar, 'cause it's from the middle of my chest to underneath my armpit and you have nothing there and you only have one breast and being like 30, I'm young yet... and it's very degrading to get it done because [when] you're a woman, your breasts are a big part of your identity.*

She emphasized that it was particularly difficult for her to lose a breast because her breasts were part of her identity as a young woman, drawing upon socio-cultural ideals related to age and femininity (Young 2003). Thus, for Melanie, losing this body part was comparable to losing part of who she is. While she had breast reconstruction not long after her surgery, she continued on to say:

*I guess the biggest thing is that it's always like having a reminder. You know, I have a huge, huge scars that I gotta spend the rest of my life with that I'm still... I don't let my husband see them. You know it's, I still keep myself covered and, you know, I still can't um, wear anything low-cut yet 'cause I'm not really comfortable with it yet.*

Melanie shared Laura's sentiments that the scars are a reminder of breast cancer and the possibility of a recurrence. In addition, she touched upon how self conscious she is of her appearance because of the scars, not wanting even her husband to see them. These comments illustrate how Melanie continues to negotiate the legacy of having breast cancer in the sense that, even after having reconstruction, she continues to struggle with the possibility of a recurrence, the changes to her body, and how others might perceive them.

Melanie's comments on the significance of breasts to her identity as a young woman indicate that the loss of a breast was threatening to her sense of femininity. Furthermore, Laura and Melanie talked about the impact of breast loss on their sexuality, because it led to a changed relationship with the remaining breast and greater self consciousness. Existing research on younger women with breast cancer has reported similar findings, with issues related to body



image being prevalent (Walsh et al. 2005). Physical changes have also been found to have negative effects on self esteem and psychological functioning in young people with cancer (Zebrack 2006, cited in Grinyer 2007, p.99). Interestingly, a study of the effects of breast cancer on younger women's relationships with partners does not discuss breast loss as a specific issue related to sexuality, instead focusing on the negative impact of side effects from treatment on sexual relations (Walsh et al. 2005). As such, future research could explore the experiences of breast loss with respect to younger and older women's intimate partner relationships in order to ascertain if differences exist.

Stacey also commented on the extensive changes that her body had undergone since her initial diagnosis. After having a modified mastectomy and reconstruction following the first breast cancer diagnosis, Stacey later had a radical mastectomy, including the removal of all breast tissue and skin in the area and a skin graft from her leg, because of a third occurrence of breast cancer. As cited in Chapter Four, she emphasized how challenging this most recent surgery had been because of the disruption it caused to her body image; specifically, the physical changes resulting from this surgery were viewed as violating, and could not be restored through reconstruction as with previous surgeries. She continued on to talk about how significant this loss was for her:

*I feel like right now I'm missing a chunk of my armour... You know, a piece of me is missing and it's an important piece because if you go out into the world, which isn't always a nice place and nice things don't always happen, you sometimes have to deal with things that are unpleasant, and when you're wearing your armour - your hair, your makeup, your clothes, all of your body parts - you feel equipped to stand up for yourself or stand up for your client or do whatever you need to do even though it's tough... Right now, I need to figure out how I'm gonna re-build that so that my emotions aren't sitting on top of my skin.*

In saying this, Stacey described the sense of loss and insecurity that she feels because of the changes to her body, connecting her confidence in how she looks to her confidence in dealing



with others, particularly at work. Thus, the physical changes that Stacey has undergone not only affect how she feels about her body but also how she feels in social interactions. Despite still being in the process of dealing with bodily changes, Stacey expressed optimism regarding the possibility of getting a custom-made prosthetic.

Although each of these three women recognized that their surgery and treatment was life-saving, they continued to struggle with how it had altered their appearance and body image. In particular, Stacey, Melanie and Laura all commented on how they managed their altered bodies with respect to what they wore. For example, Melanie commented on her experience prior to having reconstruction:

*Being 30 and getting a prosthetic breast isn't a very nice looking thing, I guess. You couldn't wear anything low cut, you couldn't wear a bathing suit, you couldn't do this or couldn't do that because any time you'd lean over, you'd see all the scars and all that kind of stuff. So I find that I'm a lot more self conscious and try to cover up a lot more. You find clothing that's, I don't know, not really less revealing but stuff that won't show my scars because I can't wear anything that's open underneath the arms or anything that's too low cut.*

This quotation highlights the impact of the mastectomy on Melanie's body and the way she dresses herself, as she continues to be more aware of her appearance and what she wears.

Stacey expressed similar feelings about having to change the way that she dresses because of her altered body, especially because of her love of fashion and pride in her appearance. She summed up her adjusted outlook on bathing suits by saying: *I guess there'll be surf shirts instead of bikinis*. This quotation is a small excerpt from a long discussion in which Stacey talked about how she would need to come to terms with her altered body and its impact on her wardrobe. Underlying this discussion are references to the loss of identity that Stacey experienced because the most recent surgery threatened her ability to take pride in her body and dress in the way that she formerly had.



Laura also discussed changes in appearance and clothing, focusing on how having a prosthetic required that she be more conscious of what she wore and limited what she could wear. She took the following two photographs to depict her choices in bathing suits and bras before and after surgery. In regards to this photograph, she said:



*This is before breast cancer and now I have to wear that (pointing to the pink one on the right), and actually it's not as bad as I thought it would be. And then I get to wear, that's my special little, um, in the water boob 'cause it has kind of has like a wing on the side because you're missing tissue there so just to, kind of fill it out so. So yeah, not quite the same. I'm looking forward to hopefully one day maybe wear a bikini again.*

She furthered her point by saying: *that [bathing suit] was the best one in the store. The other ones are like 'Oh my god, my grandma wouldn't wear this it's so ugly.'* So yeah, definitely makes me self-conscious 'cause it's not what I would choose to wear, and not what I see other people wearing. Laura discussed a similar idea in relation to the second photograph:

*It's not even being able to go to a regular bra store. Like I went from wearing a black or like cute little white lacey bra to the same bra pretty much every day because I hate all the other ones that are in the [specialty] store. Again, they're like totally not something I would choose to wear, just the styles and the material.*





Laura's comments provide evidence of how managing the physical changes that her body had undergone was further complicated by the view that her new bras and bathing suits were not designed with young women in mind, reinforcing the belief that she was going through an experience that was atypical of young adulthood.

The comments made by Stacey, Melanie, and Laura regarding breast loss emphasize their perceived need to manage their appearance, as breasts were depicted as central to being a young woman. Such comments reflect the association of women's breasts with femininity and sexuality in Western society, and the subsequent de-valuing of women whose appearance do not meet socio-cultural (male-defined) norms (Lorde 1980; Young 2003). Thus, amidst their own negotiations of self identity, these young women sought to manage their appearance in social interactions in order to maintain a sense of femininity and avoid being perceived as different. Similar findings have been reported in other research on women of all ages affected by breast cancer, although some women indicated that they chose to wear prostheses because they feel more 'balanced' physically (Thomas-MacLean 2005). However, feminist scholarship questions whether the choice to wear prostheses or have reconstruction following mastectomy actually reflects a personal preference or women's submission to socio-cultural ideals (Lorde 1980).



Further, the emphasis placed on feminine ideals of beauty by these participants may be specifically related to their age and the greater socio-cultural imperative for young women to achieve these ideals in order to maintain their sexual or reproductive attractiveness (Young 2003).

In addition to changes in clothes, bathing suits and bras, some participants also incorporated headwear into their wardrobe to conceal their hair loss. Laura indicated that she occasionally wore a wig, while other times she wore a bandana or tuque, until her hair grew back after chemotherapy. Aurelie also managed the loss of hair from having radiation therapy on one part of her head by wearing a scarf or tuque at most times, although she indicated that she did not do so while at home with her roommate. Stacey shared the experience of losing her hair during treatment, although she did not speak at length about this. Overall, these three young women seemed less concern about losing their hair than other side effects of treatment, possibly because it was not viewed as part of their body or because it was easier to manage and was often temporary (although Aurelie continued to wait for her hair to grow back). Further, these young women primarily talked about hair loss in relation to how others might perceive it, rather than their own feelings about it.

Thus, physical changes resulting from illness affected appearance and how participants dressed, as the above paragraphs describe the need to adjust the style of bras and bathing suits they wore, and incorporate shirts that did not show cleavage or underneath the arms. Further, some participants incorporated scarves and other head wear into their wardrobe in order to cover hair loss resulting from chemotherapy or radiation. Such changes in how participants dressed affected their comfort in being around other people, as several discussions about appearance were centred on how other people might perceive their changed appearance or their atypical way



of dressing. Thus, being perceived by others as different (in comparison to others or before) or having an unusual appearance was a prominent concern for these participants, which is reflective of what has been reported in the literature on young people with cancer (Grinyer 2007; Odo & Potter 2009). Further, illness was disruptive for these participants because it required them to be conscious of or change the way that they dressed, something that was taken-for-granted prior to diagnosis.

Interestingly, hair loss resulting from treatment was less prominent in the stories of the three young women who had such an experience in comparison to comments made by young women in Grinyer's (2007) study of young adults with cancer. Specifically, Stacey and Laura spoke briefly about losing their hair, while they each spoke at length about breast loss. This observation suggests that young women who lose a breast due to cancer may place more emphasis on that in comparison to hair loss because the breast loss is viewed as more permanent and central to identity, even if reconstruction follows. However, two studies of younger women (up to age 50) of breast cancer did not identify appearance or physical changes as a primary concern (Coyne & Borbasi 2006-7; Dunn & Steginga 2000), suggesting that such concerns may be more prominent for women who are in their 20s and 30s than those in their 40s who are more focused on employment, family, or other disruptions to everyday life. Explanations for this could be related to the importance of appearance to young women who are single or in the early stages of relationships, socio-cultural ideals of femininity related to age, or generational differences in the emphasis placed on appearance.



#### 5.3.4.2 Re-examining the Relationship with the Body

While participants' comments about physical changes often centred on how others might interpret them, many of the young women also offered insight into how having a serious illness affected the way that they thought about their bodies. Although the impact of illness on the relationship with the body varied among participants, none of such relationships appeared to go unchanged as a result of their illness experiences. Some participants, such as Nicole, Laura, Nancy, and Sandra, expressed anger and/or frustration regarding their bodies and its perceived malfunction. Several participants expressed a greater awareness of their physical being, including Melanie and Laura, or a desire to take better care of or be more accepting of their body, although this was not necessarily a constant feeling or something that they acted on, as evidenced by Sandra, Nancy, Leanne, and Elizabeth. Specifically, the stories told by the young women about their bodies highlight the process that was involved in coming to terms with an altered body and a changed relationship, which was well summarized by Stacey.

As a result of their illness diagnosis, participants communicated a range of emotions regarding their body. Specifically, some participants expressed anger and frustration regarding their body and its failure to function as it should. Nicole was candid about the emotions that she experiences:

*I feel like I am, um, I guess, angry at myself, um, 'cause it wasn't something I potentially did and I feel like my body was just like revolting on me... I didn't do anything to cause it so I was really upset and, um, didn't really like my body in the first place but it was like now I'm really angry, like now I hate you. I, I almost looked at my body like another person and I was just so angry. Um, I didn't feel like it was fair that it would do that but, um, it just happened so there's not much I can do about it. I was just, yeah, I don't really like it as much as I probably should. I don't really appreciate what it is.*



Nicole emphasized that her anger stems from the belief that she is not to blame for her illness because she did not invite ill health by engaging in risky health behavior. Thus, she experiences her epilepsy diagnosis as a sign of her body's rebellion against her mind's will, which has left her feeling helpless and alienated from a body that she previously was not all that fond of. Such feelings of alienation from the body call attention to the 'dys-embodiment' that occurs because of illness (Williams 1996, cited in Seale 1998), in which the body comes to be seen as a separate entity from the mind (or the self). Although she talks about the tense relationship with her body due to illness, her use of the past tense suggests that she is increasingly coming to terms with its malfunction. However, she concluded by saying: *It just feels like your own body's turning on you and you can't even rely on that*, demonstrating her ongoing frustrations regarding the perceived betrayal by her body.

Laura also highlighted the range of emotions that she feels towards her body following her breast cancer diagnosis and treatment. As someone who leads a relatively healthy life and is knowledgeable about nutrition, Laura questioned how she could have been affected by the illness. She said: *I guess also a certain feeling of helplessness that even though I did almost everything right, uh, it can still happen. Um, so yeah, a lot of anger and guilt and frustration.* Similar to Nicole, Laura focused on the idea that she did not act in a way that led to her illness, and emphasized the lack of control over her body that she feels because of this. She also alluded to the guilt and frustration that she experiences because of the potential implication of her illness for her loved ones. Thus, Nicole and Laura's comments draw upon socio-cultural discourse surrounding health in Western society in which health is portrayed as something that can be achieved through self-control and self-discipline (Lupton 2003). Therefore, these young women



struggled with the idea that, although they did not perceive themselves as engaging in unhealthy behaviours, they were still affected by serious illness, which left them feeling helpless.

Nancy was another participant who articulated definitive effects of illness on her relationship with her body. She described her current association with her body as a *love-hate relationship*, with her bouncing between two extremes. She expanded on this by saying:

*I totally have a more, um, back and forth relationship with it. Whereas 'Okay, I have to take care of myself really well', which is good. But then when shit starts to go bad I just like 'I hate my body. Whatever', you know? ...That's one of the reasons why I gave up, ah, trying to give up caffeine, if that makes sense. Okay, 'cause it's like 'Well, it's cramping anyway. Like if I just drink some coffee, like, whatever. Yeah, it's not going to do much more damage. It's already fucked, might as well give up.' And then to be able to stay awake during class, you know? So yeah.*

Nancy expressed her frustrations regarding the lack of control that she perceives to have over her body. She specifies that she has attempted to make changes in her diet in order to minimize the symptoms that she experiences, however the continuation of her symptoms makes these efforts seem futile. Thus, while she wanted to take care of her body in order to improve her health, Nancy also suggested that perhaps it was too late to rectify her ill health. Thus, similar to Nicole and Laura, Nancy's comments speak to the loss of control over the body and the resulting emotions. Other researchers have identified similar emotions resulting from the lack of control and changed relationship with the body that arises because of illnesses such as cancer (Odo & Potter 2009) and epilepsy (Raty et al. 2007).

Although Sandra's thoughts regarding her body were somewhat more compassionate than those of the participants discussed above, she also spoke to the frustration arising from her diagnosis of multiples sclerosis. She said: *I just feel bad for my body, I feel like there was a miscommunication somewhere and it sort of misunderstood what it's supposed to do and I wish*



*it didn't do that, like I wish that it worked the way it's supposed to work.* Although at other times it was apparent that Sandra struggled with the uncertainty of illness, this comment demonstrates her view that illness is not an intentional revolt by her body, instead perceiving it as a malfunction arising from miscommunication. Despite not explicitly expressing anger toward her body, Sandra's frustration is apparent in her admission that she wishes that her body would behave like *it* should. Therefore, like the young women discussed above, Sandra expressed a sense of helplessness because she could not control her body or ameliorate the problem that was causing her to be ill. Again, the language used by Sandra, specifically the repeated description of her body as *it*, calls attention to the experience of dys-embodiment that results from the separation of mind and body imposed by illness (Williams 1996, cited in Seale 1998).

Melanie spoke of the increased attention she paid to her body, focusing on how this has led her to seek out other medical tests to ensure that she is cancer-free. She said:

*So [having cancer] definitely made me more aware of my body now too with everything that's going on, and getting things checked out and making sure that it hasn't spread because I have a very high chance of getting it back. But, um, it's just a matter of going for check-ups and yearly exams and mammograms and everything to make sure that I stay on it. And knowing my body too is the biggest thing.*

Her comments speak to her heightened awareness of illness, and the threat that cancer poses to her faith in the health of her body. As a result, she has come to question her body and whether further illness awaits detection. Ongoing concerns regarding recurrence are common for breast cancer survivors, who may feel that they are “never free of cancer” (Burles 2006), which I further discuss in the upcoming section on feelings of uncertainty in Chapter Six.

Laura expressed similar concerns as Melanie regarding the possibility of recurrence and its impact on her relationship with her body. However, she noted that her fears are diminishing somewhat as time passes since her diagnosis and treatment. Thus, while her relationship to her



body has been forever changed, Laura's distrust of her body is lessening as she comes to accept what she has been through. Her comments raise an interesting issue related to her relationship with her body; specifically, Laura's trust in her body prior to diagnosis reflects the suspension of the "fundamental anxiety", fear of death, in order to live out her life (Schutz 1971, cited in Good 1994, p. 127). However, this former trust was ultimately exposed as false by her diagnosis, suggesting that she may have reason to be wary of a further betrayal by her body. However, Laura, similar to Melanie, Stacey and Aurelie, needed to re-gain her previous trust in her body in order to move on with life and suspend the awareness of her mortality that cancer brought about – that is, to return to a state in which her being-in-the-world was taken-for-granted.

In addition to negative emotions regarding the body and its malfunction, some participants described a heightened awareness of the body resulting from illness in positive terms. Melissa summed this up by saying: *Now I'm very in tune with what my body does and does not approve of, including certain foods.* She also described the need to have a *crash day* on occasion in order to restore her energy supply. Thus, Melissa's comments emphasize her realization that her body is largely in control of what she can and cannot do, and the need to listen to her body's messages.

Leanne also talked about the changed relationship that she has with her body as a result of her illness, expressing greater acceptance toward the size and appearance of her body. She used the following photograph of the mall in her city to discuss *the rollercoaster ride* that this relationship had endured:

*Before I was sick I would, I used to dread going to the mall because nothing would ever fit and I would always feel horrible and gross and disgusting about myself. And then, um, [when] I started losing weight, I liked going to the mall and things fit and I looked good in them. And then when I was really sick, all I remember is going into one store and, you know, I was small and I was sick and I was emaciated and I was not healthy and stuff still*



*not fitting, and I remember at that time feeling horrible... And now I like going again. It's fun... now, even if something doesn't fit, that's okay, whereas before it would have been like, well, when I was really big it would have been like '(exhaling)', you know, such a horrible effect on my self-esteem. And then when I was sick, it still affected my self-esteem. So now, if something doesn't fit, it's just like 'Oh well, that sucks.' But it's not like, I don't dwell on it.*



Leanne documented the ups and downs in her feelings toward her body that accompanied the variance in her weight and self esteem. She indicated that, now that she has moved past the anorexia, she has a more realistic perspective towards her body and no longer associates her worth with her appearance. Thus, although Leanne's history of illness is now largely invisible except for the tracheotomy scar, her physical being is endowed with changed meaning as a result of illness.

Elizabeth noted similar shifts in her relationship with her body due to the illness experience. She stated that the apathy resulting from depression included apathy towards her body and self-care during that time. As a result, Elizabeth feels that she was not as healthy while depressed and may have weighed more than she did prior and currently does. She continued on to say that she no longer feels physically and metaphorically dragged down by depression, and seeks to improve her overall well being through practices like yoga. Thus, while Elizabeth may



not have experienced physical changes because of illness, she described her relationship as being affected by depression.

Sandra, who was still dealing with the uncertain implications of MS, discussed how illness had prompted to think more about how she treated her body. She used a photograph of a carafe of water to illustrate the importance of taking steps toward good health. She described the photograph, saying:

*This is water (laughs), um, one of the aspects of good health is taking care of oneself in general, and I haven't got to the point of being healthy enough that I am exercising regularly and eating well and losing weight and being strong and fit - I'm not there yet... But one of the things that I can do and I try to be very conscious of is water intake.*



While Sandra admitted that she has further steps to take to become healthier, having to negotiate MS has placed greater emphasis on the need to be proactive about her health. As mentioned earlier, Nancy also considered taking steps to better care for her body in light of illness, although her desire to do so was thwarted by the lack of impact of changes in diet on her symptoms of illness.

In the above discussion, I demonstrate that illness had a variety of implications for the participants' relationships with their bodies. While many of the young women endured both



negative and positive effects of illness on how they felt about their body, Stacey articulated how time was necessary to adjust to physical changes and the altered relationship with the body resulting from illness:

*It definitely weathered a huge storm, that relationship, this last year because in all prior circumstances [my body] still appeared to be pretty much the way it always was, you know, no matter how many extra scars there were or whatever. This is the first time there's a whole part of missing and it's never coming back, you know? There'll be a plastic one, but you take it off at the end of the day. And that was weighing really, really heavily on me, but I think it was just a thing that needed some time to absorb, because now it doesn't seem as earth-shattering as it did even two months ago. Um, and I think part of that is emotional healing goes with the physical healing and, and, you know, there's no more dressing and it doesn't hurt anymore and it's not as high maintenance, and I can watch it fade and as it fades the fear and the obsession is fading with it, and I'm coming to terms with it.*

Stacey highlighted the process involved in negotiating bodily changes and their implications for identity. As she commented, her outlook on her body had improved tremendously between the two interviews as she came to recognize that the physical changes to her body did not affect who she was, despite having placed much emphasis on her appearance in the past. In this sense, she summed up the process that all of the participants were amidst – trying to make sense of the bodily implications of illness in order to move forward in other areas of their lives.

This sub-theme addresses a number of important issues that the participants experienced in relation to illness and its effects on their bodies. In particular, some of the young women expressed feelings of anger and/or frustration toward their bodies as a result of illness, in that it led them to feel helpless or betrayed by the body (Nicole, Laura, Nancy, Sandra). Such feelings are similar to those expressed in a study of women affected by breast cancer, in which illness was a sign that individuals are at their body's mercy (Thomas-MacLean 2008). Reconciling with the ill body was particularly difficult for individuals who did not understand why illness came about or felt that they should not be ill because they led healthy lives (Laura, Nicole). Thus, for



these participants, illness exposed the falsehood of widespread Western belief in the ability of individuals to control their health through personal behaviour (Lupton 2003).

Some of the young women also discussed their greater awareness of their body, which for some was connected to monitoring the body for further signs of illness (Melanie, Laura). Another participant felt she came to know her body better because of illness (Melissa). In addition, one participant became more accepting of her body than in the past (Leanne), while others considered being more proactive in taking care of their bodies (Elizabeth, Sandra, Nancy). Although there was variance in how illness affected young women's relationships with their bodies, one participant, Stacey, illuminated the process by which adjustment to and acceptance of the changed body came about, emphasizing the need to incorporate physical changes into self identity in order to manage their implications.

### *5.3.5 Summary*

In this theme, I address the disruptions that illness and treatment brought about in participants' everyday lives. I identified four sub-themes that capture different aspects of the changes that illness brought about in everyday life. First, some participants experienced treatment as disruptive because it affected their everyday roles and the organization of their lives. For instance, these participants' schedules became organized around treatment appointments and side effects, making it difficult for them to carry on with their usual activities. While Laura and Melanie were able to modify their roles, Stacey and Aurelie experienced greater disruptions, due to the need to travel for treatment and the physical impact of treatment respectively. Leanne experienced the most drastic disruption due to her three month hospitalization because she was



completely removed from her former life and social roles. Thus, participants experienced disruptions or setbacks due to illness because it altered their ability to fulfill past responsibilities and continue with their lives in the way that they had previously planned. However, these participants were also able to resume many of their former roles or take on new roles following treatment, and therefore many disruptions were characterized as short term.

In addition, several participants were required to integrate medication regimens into their everyday routines. Some participants found this particularly difficult and resented this change in their lives. Particularly, Nicole and Sandra found taking medication and the side effects to be burdensome and limited their freedom. Nancy struggled further with having to make decisions regarding treatment each day, in addition to managing the side effects and inefficiency of some medications. Thus, these participants were faced with decisions about whether the perceived benefits of medications outweighed the perceived limitations. This observation is evidenced in Aurelie's comments regarding her acceptance that medication will likely be a part of the rest of her life, as she understands its ongoing importance to her well being.

In the third sub-theme, I highlight some of the limitations that arose for participants because of illness. Specifically, changes in physical ability because of illness resulted in greater caution and the inability to carry out some former activities, particularly some leisure activities. Thus, physical limitations affected how some participants thought of themselves, as well as their relationships with others. Limitations that resulted in dependence on others were particularly significant to some participants, which is comparable to the findings of existing literature on young adults with cancer (Grinyer 2007). Thus, limitations resulting from illness had profound effects on some participants' psychological and social well being, as it altered their ability to perform past activities and roles and their relationships with others.



Finally, the fourth sub-theme highlights participants' experiences of having an altered body and relationship with the body. Issues related to appearance, body image, femininity, and sexuality emerged as pertinent to some participants, particularly those who had undergone surgery, and thus experienced drastic physical changes, as a result of illness. The three young women affected by breast cancer reported having to change their style of clothing to accommodate for their breast loss and scars. As well, these participants experienced the loss of a breast as detrimental to their identity and their sense of femininity. As young women, they perceived breasts as being important to their identity, with Stacey also noting that her recent surgery had generated feelings of vulnerability that affected her identity and composure in social interactions. Finally, hair loss was also addressed by three of the participants, although this experience was viewed as less permanent and superficial than other losses resulting from illness.

While not all participants experienced a change in their physical state, each described the impact of illness on the relationship with their body. Some participants expressed negative feelings toward their body, including anger, frustration, alienation, betrayal, and confusion, showing the pronounced impact that illness had. Further, some participants' comments highlight the separation of mind and body as a result of illness, in that the body was discussed as being a separate or objective entity from the mind. Such comments highlight the helplessness and loss of control that participants experienced because of illness. Trust in the body had been diminished by illness, as reflected by comments regarding the body's betrayal, as well as some participants' heightened awareness of their body. Despite overwhelmingly negative implications for the relationship with the body, some participants reported positive outcomes of illness, such as being more in tune with or accepting of their body. Further, some participants expressed a desire to take better care of their body, although their health behaviour had not necessarily improved.



Stacey summarized the process involved with incorporating physical changes or a different relationship with the body into self identity, suggesting that time for adjustment was crucial.

In this chapter, I have explored the embodied experience of illness for participants, highlighting how they discerned and learned about illness, as well as managed the disruptions brought about by illness and its treatment to everyday lives. In the following chapter, I shift the focus to how participants experienced serious illness with respect to its timing, highlighting the need to negotiate illness with respect to disruptions to the life course, and relationships and social support.



## **Chapter Six – Situating the Illness Experience in the Life Course**

*Sometimes I feel left behind because everyone that is our age is going through things that we're not participating in yet [because of illness] and who knows if we will. (Stacey, breast cancer)*

### **6.1 Introduction**

In this chapter, I examine temporality and relationality in participants' accounts of illness. Specifically, I seek to contextualize their illness experiences by identifying the disjuncture between illness and how they envisioned their current position in the life course, as well as their expectations for the future. I discuss themes related to: illness as a disruption to the life course, and the negotiation of social relationships and support during the illness experience. Each of the themes is divided into sub-themes that highlight different aspects of the broader theme and offer specific illustrations of the young women's experiences. My intent in this chapter is to draw attention to participants' psychosocial experiences of illness, as they faced a number of issues that required psychological consideration as well as interpersonal negotiation. Further, the young women experienced illness within a wider social context through their engagement with socio-cultural expectations for the life course and various discourses on health and illness.

### **6.2 Illness as Disruptive to the Life Course**

In this theme, I describe the various ways that participants experienced serious illness as disruptive to their identities as young women or their expectations for this time of life. I have divided this theme into three sub-themes, which are: feeling abnormal and "off time", managing threats to well-being, and re-negotiating expectations for young adulthood and the future. The



second sub-theme has been further categorized into sub-sections about: feeling vulnerable, facing uncertainty, and realizing mortality. As a whole, this theme highlights how participants experienced illness with respect to their position in the life course, and how illness was felt to be inconsistent with other aspects of their lives. While many of the young women faced issues that have been identified in the existing literature on illness experiences, I seek to demonstrate that participants also experienced and made sense of illness in unique ways because of their life stage.

#### 6.2.1 *Feeling abnormal and “off time”*

Herein, I discuss participants’ reflections on their experiences in comparison to other young adults, and other individuals affected by serious illness. The threat that illness posed to ‘normality’ was evident in the stories of several of the young women, who recognized that being ill made them different from many of their peers. Specifically, illness introduced limitations or setbacks into their lives that led them to be different from their peers. In addition, illness was perceived by many of the participants as throwing them “off time” with respect to their life course trajectory, demonstrating their awareness of common characteristics associated with young adulthood. The concept of being “off time” emerges from the research of B.R. Williams (2004) on terminally ill cancer patients from low socio-economic backgrounds in the United States, and refers to the belief that an individual’s illness and/or death is occurring at an atypical time with respect to socio-cultural constructions of the life course. Thus, illness resulted in experiences that were viewed as being typical of individuals older than themselves, as well as younger than themselves on occasion. Further, some of the young women described being unable



to relate to others affected by the same illness because of the different timing of illness in the life course. The examples that I highlight with respect to this sub-theme contribute to the notion that illness was disruptive to the young women's perceived position in the life course.

First, several comments were made by participants with respect to their feelings of abnormality and the desire to be like other people their age. For example, Nancy and Leanne referred to feelings of abnormality, commenting respectively: *It's like 'Okay! I just kind of want to be normal for once.'* and *I still didn't get why, why it happened to me? Why I couldn't be normal?* Such feelings were also communicated by Sandra who recognized that her illness, along with other aspects of her life, made her unlike many other individuals in their mid-30s. Nicole also suggested that she was different from other people her age, saying that: *They have a little bit more of a normal life than I do, like they can go out and they don't have to worry about taking the medication.* Melissa also recognized that being ill caused her to be different than what would be expected of most young adults, recalling: *How many 23 year olds sleep that much [16 to 18 hours] a day?* Thus, these participants communicated feelings of difference from others their age as a result of illness and the limitations that it imposed. Such feelings are similar to those reported by young adult cancer survivors, for whom the illness experience magnified the sense of difference and isolation that they felt from their peers (Lee 2001; Odo & Potter 2009).

As the above comments demonstrate, feeling different or abnormal was a common experience for many of the participants. Negotiating feelings of abnormality may be particularly crucial for young adults because acceptance by peers is critical to this development stage (Lee 2001; Thornes 2001, cited in Grinyer 2007, p.75). Such feelings are significant in that they can contribute to a sense of alienation from others and "the breakdown of a commonly shared reality" (Good 1994, p.125). As such, feeling abnormal because of illness threatens one's sense



of belonging and comfort in social interactions, which may hinder seeking support and psychosocial adjustment to illness. Further, Grant and Roberts (1998) suggest that perceived peer acceptance and belonging affect feelings of self-worth (cited in Grinyer 2007, p.75). Thus, feeling abnormal can lead young adults to view themselves as having departed from ‘normal development’, which may contribute to frustration, self esteem and/or identity issues, relationship troubles, and difficulty making sense of illness (Lee; Odo & Potter 2009).

In addition to expressing feelings of difference, Nicole and Leanne discussed the timing of their diagnosis as being unusual, making them feel abnormal. Specifically, they perceived their respective illnesses to be more common in younger individuals. For example, Leanne indicated that the time in her life at which anorexia occurred posed challenges to her care and support, saying: *Every single doctor I saw was like ‘We don’t know what to do. Your case is so unique.’ ... It felt like, like ‘trial and error.’ They’re trying to see what’s working, what’s not. Because, you know, my onset was so quick [and] I was a lot older than the typical start age.* Accordingly, the unique timing of her illness, compounded with her diverse medical and psychological needs, meant that many of Leanne’s care and support needs went unfulfilled because of health care providers’ unfamiliarity with patients experiencing a first occurrence of anorexia in their 20s. Nicole shared a similar experience of being diagnosed with epilepsy at an age that was older than typical, believing that doctors were unsure of how to deal with her unusual case. Thus, both Leanne and Nicole attributed feelings of abnormality to health care providers being ill-equipped to deal with their support and informational needs.

On the other hand, some participants experienced their diagnoses as “off time” because of the other events happening at the time, in addition to perceptions that the illness by which they were affected was typical of older individuals. For example, Stacey experienced her initial



diagnosis of breast cancer at age 29 as unexpected and highly disruptive to her promising career. Similarly, Melanie experienced her diagnosis as highly disruptive to her role as a wife and mother of two small children. Several other participants also talked about the disruption caused by illness to educational and employment aspirations. These examples demonstrate how the timing of illness was perceived as inconsistent with their other social roles and contributed to the belief that it was “off time”, despite that many young adults are affected by serious illness.

In addition, the side effects of treatment caused some young women to feel as if their body was going through things more common to older women. Primarily, Stacey and Laura both experienced menopausal symptoms due to their breast cancer treatment. Stacey summed up her feelings regarding this experience:

*It's like forcing a thirty year old, or I guess a thirty three year old at that time, to live in their mother's body because suddenly you've got, um, you know, hot flashes, um, you know, more peach fuzz on your face, like just, you know, the things that happen to an older woman but they're happening to you at the wrong time.*

Stacey emphasized how she viewed this experience with respect to her position in the life course, as she perceived menopause to be an experience more consistent with someone her mother's age than her own.

Nancy expressed a similar sentiment regarding the possibility of chemically-induced menopause as a treatment for endometriosis. She sarcastically exclaimed: *It's like 'Whoa! Okay, yeah, menopause in my 20s. Cool, like, that's awesome.'* In saying this, Nancy also highlighted the view that menopause was inconsistent with the typical bodily experiences of young adulthood. These comments regarding the possibility of entering menopause during this life stage highlight an important issue: that the physical implications of serious illness can contribute to inconsistency between how young people feel and their perceived position in the life course.



In particular, this inconsistency emerges because the physical experience of illness is typically unknown to others their age (Lee 2001).

As well as causing some participants to view the body as being “off time”, illness could also hinder the young women’s opportunities to act like other people their age. As discussed previously, Nicole and Aurelie felt that they could no longer enjoy a night out with their friends at the bar in the same way as they had in the past because of: fatigue, the risk of a seizure, mobility issues, and/or potential interaction between alcohol and medications. Nicole communicated how this restriction led her to feel different from others her age:

*I guess I feel really limited being [an] age that a lot of people do go out to the bar and, um, drinking’s a big thing for them... Even if I did want to go out to the bar, I know that I wouldn’t stay very long because I’d feel sick and it’s just, it’s exhausting for me... I just feel a little bit left out sometimes.*

As a result, Nicole experienced her illness as disruptive to her social life and ability to be like other people her age, an experience that was also evident in Aurelie’s comments. Their experiences echo a proposition made in a case study of a young cancer survivor that the illness experience sets young adults apart from others their age (Lee 2001).

Stacey also articulated how having breast cancer three times during her 30s had put her “off time” by talking about her and her husband in comparison to other couples. She related:

*We’re sort of trapped between different groups and we don’t necessarily fit anywhere ‘cause we are this anomaly where we’re going through this disease at a time that isn’t as common, we are approaching our 40s and don’t have a family... (sighs) We sort of belong to a bunch of different groups that none of them are really an exact fit. When I think socially, we have lots in common with people who are single or, you know, quite young, in their early 20s, because we can pick up and go whenever. We, you know, we don’t have the same obligations, um, we don’t have a family we have to worry about, that kind of thing. Um, sometimes I feel left behind because everyone that is our age is going through things that we’re not participating in yet and who knows if we will. Um, and then we don’t necessarily fit with people that are just a little bit older than us because now they’re, some of them are becoming grandparents and they’re in a different place too.*



Stating that she sometimes feels *left behind*, Stacey's comments provide evidence of how being ill has shifted her and her husband off of a perceived normal life course trajectory. Specifically, she noted that not having children made them different than other couples their age, as well as unique to other couples going through a breast cancer experience who are typically older and may have children and/or grandchildren. Laura shared a similar experience of watching other people in her age group have children while she was waiting until the completion of hormone therapy to see if she will be able to have children of her own. She summed up her feelings of not being able to go through this common experience of young adulthood by saying: *My younger sister's pregnant right now, so that's hard.*

Laura returned to this idea at other points during the interviews in order to emphasize that she felt unique in comparison to other women with breast cancer. Thus, in addition to feeling different from other young adults, she indicated that she had trouble relating to women who had also experienced breast cancer:

*I actually did join [an exercise group for women affected by breast cancer] because I'm interested in being physically active and things like that, So, uh, but again, it's like, I feel like I don't fit with them, either because I think the next, you know, person closest to my age is in their 40s or something like that... I mean still, we've had this same experiences and get to talk... So it's been good but I also feel like 'Well, I don't have kids, and I don't have grandkids.' And I just, yeah, have a hard time, um, connecting really, with them now that I'm okay.*

Laura communicated that she perceives herself as being unique to the other women in the breast cancer exercise group because she is much younger. She further elaborated on her feelings of difference, saying:

*It's one thing to sort of have lived your life for the most part, and I mean [breast cancer] always sucks as a grandma, as mom and as a what have you, but at least you've kind of had your chance and that's often in the back of mind 'Well you've had the chance to have children and things like that.' ...I mean I just feel like I don't have that much in common*



*with [older women]... beyond similar medications, and actually I just think about how it's just wrong that I should be in the same sort of situation as them.*

Here, she acknowledged that older individuals who are facing a life-threatening illness such as breast cancer are in a different position than younger individuals who have yet to fulfill many developmental tasks and goals for their lives, such as raising a family. Further, Laura emphasized her belief that it is unjust to be facing the possibility of a shortened life course because she has several goals that she would like to accomplish.

Stacey also called attention to the unique situation of young women with breast cancer, which may also speak to the experiences of young women with other serious illnesses. She did so by recalling her initial encounter with a breast cancer survivor:

*At the very beginning of all of this, [a woman from] a hospital visitation program, came to the hospital to see me. Well, the lovely woman who came had to be at least 70, you know, and she's talking to me about my brazier, right? And so I was feeling bad for her, she's feeling scared of me, nobody's connecting because I have really practical questions that probably need to be answered that she's not going to have the answers for, and not going to be comfortable talking about them anyway.*

Stacey, who would have been approximately 30 years old when this interaction took place, appreciated the gesture of support that was being offered by the volunteer but intimated that someone 40 years older than her was not able to answer the practical questions that she had regarding issues such as: menstruation, prosthetics, fertility, and the side effects of treatment. Stacey's recollection of the volunteer's use of the word *brazier* demonstrates the disconnection between her and Stacey, as younger women would simply refer to this undergarment as a bra.

The above paragraphs highlight participants' experiences of feeling different in comparison to others their age and other individuals affected by the same illness. Their stories suggest that illness caused the majority of young women to feel "off time" with respect to their perceived position in the life course. Being ill during young adulthood led participants to feel



either younger or older than others individuals affected by illness, as well as different from their peers. Nicole summed up the feelings of many participants by noting that the burdens brought about by illness, such as having to take medication, contrasted with the characterization of young adulthood as a carefree time of life. Such a sentiment is also evident in existing research on young adults with serious illnesses who report being overwhelmed by the time-consuming nature of illness (Badlan 2006) or feel misunderstood by others their age who do not have concerns of such magnitude (Odo & Potter 2009). Further, some participants did not relate to individuals of other ages affected by the same illness, noting that being diagnosed during young adulthood contributed to unique experiences of illness and its consequences.

Additionally, participants talked at various times about how illness hindered their ability to fulfill goals that are common to this life stage, including those related to: social life, education, employment, and family. Laura's comment that it is unfair to face a life-threatening illness as a young adult reflects the socio-cultural portrayal of illness as being associated with aging (S.J. Williams 2003), as well as widespread belief in the value of young people and their potential contributions to society (Jecker & Schneiderman 1994). As such, participants' experiences of feeling "off time" due to illness demonstrate their awareness of such characterizations of illness and the life course, and the influence of these characterizations on how illness was experienced and understood. Therefore, many participants experienced feelings of abnormality as a result of becoming ill during young adulthood because it threatened their ability to feel and behave in the way that is typical of this life stage.

This sub-theme highlights issues related to the social construction of the life course and how socio-cultural expectations can be problematic for young adults experiencing serious illness. Specifically, participants viewed illness as being "off time" with young adulthood, even when



the timing of their diagnoses were: later in life than average (Nicole, Leanne), common for that type of illness (Sandra), or becoming increasingly more frequent (Stacey, Laura, Melanie). Therefore, the struggle with feeling “off time” was more related to being out of line with socio-cultural expectations, rather than any universal experiences of the life course. For instance, disruptions to education, employment, leisure activities, and the establishment of an intimate relationship or family brought about by illness were viewed as significant by many participants, despite that many young adults do not actually pursue or achieve such goals. Further, feelings of difference from other young adults or other individuals affected by illness may emerge whether or not the timing of illness is atypical or not. Consequently, the influence of socio-cultural expectations for young adulthood on participants’ perceptions of illness suggests the importance of exposing such expectations as arbitrary and socially constructed in order to alleviate young adults’ feelings of being abnormal and “off time”. Specifically, re-envisioning a ‘full’ life course as one of any duration could lessen feelings of difference and the mourning of lost opportunities. However, revising expectations surrounding the life course to account for diversity cannot ameliorate all of the losses or potential losses that young adults face due to illness because some goals are linked to structural or biological conditions, such as education or employment opportunities and the ability to bear children.

### *6.2.2 Managing Threats to Well Being*

This sub-theme highlights how illness placed participants’ well being in jeopardy. I have divided the sub-theme into three categories that explore the young women’s discussions of feelings of vulnerability and uncertainty, and how illness led them to realize their mortality. The



participants shared reflections on how illness had changed the way that they thought of themselves and the future. Thus, illness had significant implications for self identity and required the young women to adjust their perceptions of the control that they possessed in their everyday lives. In highlighting such feelings and experiences, I demonstrate the disruptiveness of illness to participants' psychological and emotional well being, and identify issues facing these young women which are both similar and unique to other individuals affected by serious illnesses.

#### 6.2.2.1 Feeling Vulnerable

Some of the participants addressed the impact that being ill had on their sense of well being. Specifically, the illness experience was a catalyst for some young women to recognize their vulnerability. Participants' discussions of vulnerability were linked to the threat that illness posed to their taken-for-granted assumptions about their bodies and lives, and the realization that their assumption that "the present extends indefinitely" was untrue (Good 1994, p.127). Perceptions of invincibility often held by young people and the threat that serious illness poses to them have been identified in research by Miedema et al. (2007), who found that young adults with cancer described themselves as seemingly invincible prior to diagnosis. As such, the diagnosis of a serious illness like cancer can have significant ramifications for young adults' perceptions of well being and may introduce greater caution into their lives. In addition to exposing vulnerability, illness shook some participants' sense of independence and perceptions of control.

For example, Elizabeth discussed the realization of vulnerability and the lasting impact that having depression had on her identity. She described how depression had changed the way



that she viewed herself as a young person, saying: *I think [depression has] taken away my sense of, you know, my invincibility, especially being a youth.* When asked to elaborate on this perceived loss of invincibility, Elizabeth said: *I think this is directly related to age. I think [depression has] also kind of reworked a lot of my idealisms of youth... Kinda, just like the mentality like 'I can handle things fine on my own. I don't need your help.'* Here, Elizabeth described the challenge that depression posed to her identity as a young woman and recently established independence. As discussed previously, independence is a significant issue identified in the literature on young adults with cancer (see for example, Grinyer 2007). Thus, Elizabeth realized that she was more vulnerable than she formerly believed, and that she sometimes required the support of others. Thus, similar to comments made by Melissa and Leanne reported in Chapter Five, Elizabeth's experience of illness threatened her independence, which she linked to her previous sense of invincibility.

Laura also experienced her illness diagnosis as a revelation that her former feelings of security had been false. Specifically, Laura described how she had downplayed the likelihood that the lump in her breast was cancerous prior to her diagnosis:

*That was one of the things that kept me from freaking out when I had this lump growing inside of me for two years. It's like 'Well, my mom's fine, I've got three older sisters. I've got, you know, grandmas that lived into ripe, a ripe old age.' I'm like 'I'm fine 'cause I don't have a family history.' It's kind of the reverse thinking... There's kind of two sides to the family history thing. I think people think that they're safe if they don't have [a family history], um, but not realizing that most cases actually don't have a family history.*

Laura related that she considered the possibility that she could have cancer but decided it was unlikely given her family history. In doing so, Laura drew on common beliefs, or a phenomenological 'typification' (Bentz & Rehorick 2008), regarding breast cancer risk in order to downplay such a possibility. Interestingly, Laura's father was affected by prostate cancer,



which was not thought to be pertinent to her family history. Laura's experience reflects the lack of awareness of the impact of paternal family history on breast cancer risk in women and health care providers that has been reported in existing studies (Katapodi & Aouizerat 2005; Yong, Zhou & Lee 2003). As such, Laura's diagnosis exposed the false sense of security that she felt because she did not have a maternal history of breast cancer.

Stacey also talked about feelings of vulnerability that arose from having breast cancer by drawing a connection between physical changes and her self assurance. As discussed previously, she experienced her third surgery, a radical mastectomy, as damaging to her self identity and confidence because it threatened her ability to feel complete and to deal with the unpleasantness that may arise in certain social interactions. She summed up her feelings regarding her mastectomy site by saying: *The best way to describe it is like armour and there's a big hole right now, a big vulnerable hole*. Stacey's use of comparative language serves to illustrate her feelings of vulnerability; specifically, the image of armour with a hole in it evokes the idea that part of her has been left exposed by her surgery and open to threats to her well being. However, she also noted: *I'm in a better place about [the surgery site] now then I was at the beginning*, showing the gradual diminishment of her feelings of vulnerability along with the healing process.

Nicole also experienced a greater sense of vulnerability as a result of her illness diagnosis and the concerns that it raised in her loved ones. As discussed in Chapter Four, Nicole's parents, as well as her boyfriend and his parents, expressed concerns over her riding a motorbike, an activity that she previously found empowering. While Nicole felt that she was safe to do so because she would recognize the warning signs of an epileptic seizure, she was also cognisant of the risk that she was taking. She related: *In the back of my mind I think about it... So I'm little bit concerned, um, yeah, I guess, I would be a little bit worried about something happening so if I'm*



*feeling the least bit not okay, a little bit sick, I won't go.* Nicole's comments emphasize the tension between her desire to continue doing something that she enjoys and the concerns that she and others have regarding her safety. Thus, Nicole faced feelings of vulnerability that contributed to greater caution when riding her motorbike, although she refused to let these feelings completely limit this activity. This example demonstrates how Nicole's faith in her body and its capabilities came into question because of illness.

Other participants shared Nicole's experience of lacking certainty of what the body would or could do. For example, Nancy expressed uncertainty regarding how her life may continue to be affected by endometriosis because of the unpredictability and debilitating nature of her symptoms. She said: *So I've just kind of like been hoping that [endometriosis] doesn't become a work issue. But, I mean, it's always going to be I think. Well, it's kind of like a life-interrupting issue. It's like you can't really control it.* The feelings that Nancy described call attention to how illness contributed to her belief that she did not possess control in her everyday life in that it had become dictated by illness. As such, she felt vulnerable and helpless despite being hopeful that her symptoms would diminish.

The realization of vulnerability described by participants above points to an important issue related to the experience of illness: the issue of control. In particular, illness and the resulting physical and psychosocial consequences brought about awareness that the degree of control (over the body and many aspects of everyday life) that individuals possess is less than previously thought. As such, illness led some of the young women to feel vulnerable as they came to realize that their prior perceptions of independence and control were somewhat fictitious. The issue of control is also evident in the young women's discussions of the changed relationship with the body described in Chapter Five, as some participants described feeling as if



their sense of control had been betrayed by their body's dysfunction. Therefore, many of the young women in this study experienced a perceived loss of control because illness exposed their vulnerabilities and inability to determine what they could and could not do (their agency). Consequently, illness threatened participants' identities as young adults that were founded on feelings of invincibility, independence, and the possession of control.

The impact of illness on perceptions of control has been discussed to some extent in existing literature. Perceived control is often connected to ill individuals' belief in whether they and/or their health care providers are able to control the cause, course, treatment, and side effects of illness (Henderson & Donatelle 2003; Newsom et al. 1996, cited in Link et al. 2004). In other words, perceived control results from the belief that agency is available with respect to illness. Perceptions of control or agency have been found to be associated with psychosocial well being for individuals with chronic illnesses (see studies cited in Hay 2010, p.260) and important to coping and adjustment for individuals with cancer (Barez et al. 2009; Link et al. 2004). Correspondingly, the perceived loss of control due to illness has significant implications for psychosocial well being and adjustment for ill individuals. While some young women struggled to cope with feelings of vulnerability and helplessness, participants generally sought to manage these feelings through efforts to re-negotiate self identity and/or carry on with their lives.

#### 6.2.2.2 Facing Uncertainty

Another theme that emerged out of the interviews with the young women was related to the uncertainty that was introduced into their lives because of illness. Uncertainty was associated with: an unknown illness trajectory, whether cancer cells remained in the body, the possibility of



future episodes of illness, and/or future outcomes of treatment. As a result, some of the participants and their health care providers continued to monitor their bodies for signs of illness, while others sought strategies for dealing with potential outcomes that could arise in the future. The young women's comments speak to the struggles that they faced and their desire for greater certainty and predictability in their lives. However, figuring out how to manage illness and the resulting uncertainty was a process involving ongoing realizations and negotiations.

First of all, many participants struggled with not knowing what direction their illness would take. For example, when I asked Aurélie about what it was like being diagnosed with a brain tumour as a young adult, she responded: *It's a bit more difficult because there are no statistics at all for [young adults] and, um, so you don't know what to expect.* As a result, her and her family were thrust into a challenging position in which they lacked existing information about survival and recurrence rates. At the time that I interviewed Aurélie, she had completed intensive treatment and had been told that she was *stable*; however, it was clear that she did not feel that stability had necessarily returned to her life and she continued to go for MRI scans every three months along with various other check-ups. With respect to the possibility of a recurrence, she said: *The doctors are always pessimistic... So they tell you the tumour will come again... But, um, uh, they told me that after 5 years, uh, it has less chance.* In making these comments, Aurelie highlighted the great uncertainty that she continues to face and the need for ongoing contact with the health care system. Such an experience of uncertainty has been described with respect to individuals affected by cancer who reportedly live in a state of "liminality" because the uncertainty of their future shifts them into the threshold between life and death (Little et al. 1998; McKenzie & Crouch 2004).



In a similar vein, Melanie and Laura both talked about the possibility that cancer remained within their bodies or that they would have a recurrence. Melanie clearly stated her concerns, saying that: *Another big thing is that when they took some lymph nodes out from underneath my arm, they found cells in the lymph nodes but they said they were dying cells so they figure they were filtered off when they did my biopsy. But did they get them all? Did they not get them all? Who's to say?* In posing such questions, Melanie raised the possibility that cancer had spread to her lymphatic system and thus remained in her body following the mastectomy that she had. Laura shared this concern, noting that her fears persisted during treatment and since it had been complete. She recalled a recent bout of fear regarding the possibility of recurrence:

*Last week I wasn't feeling well, I had stuff going on, um, and I felt dizzy a couple, a few days last week and I still freak out. If anything lasts more than two or three days, I'm like 'Oh, my god, I have metastatic breast cancer.' It's, I can't, like I can be as rational as I want and it's still there and the longer I don't feel well, the more I'm like 'Okay, this is it.' You know? So I mean, I don't know that that'll ever completely go away. It's definitely gotten a lot better, absolutely. I don't worry about it every moment of every day anymore but when I'm not feeling well, it just, it's a reminder of, or if I'm feeling really tired and I don't know why, it's just like 'Oh god.' So it's always kind of there and breast cancer is so notorious for coming back five, ten and fifteen, twenty years later.*

This comment from Laura's interview illustrates how her heightened awareness has led to uncertainty in her life because she interprets any symptom as a possible indication that cancer has returned, an experience commonly reported by breast cancer survivors (Burles 2006; Gil et al. 2004). Laura also speculated that a recurrence was likely given the nature of breast cancer, a belief shared by Melanie. Thus, Melanie and Laura continue to live in a state of "liminality" (Little et al. 1998) similar to Aurelie in that they do not know if cancer will return, or when and where, resulting in the diligent monitoring of their bodies.

Interestingly, Stacey's experience reflects the concerns of Laura and Melanie regarding the likelihood of a breast cancer recurrence. In particular, I met Stacey after her third breast



cancer diagnosis in approximately seven years. When asked about the possibility of dealing with cancer again in the future, Stacey articulated her feelings regarding the uncertainty that she faces:

*I don't know if I have really made some real conscious decisions about how I feel about [the possibility of another recurrence], um, I don't know. Sometimes I worry that I'm a self-fulfilling prophecy because I never felt like it was really over, so I don't know whether you just inside you somewhere know your body so well to know that it's not over, or you think it into being. I'm hoping it's the first not the second. I don't know if it will ever be over, um, even if it doesn't come back it's never really over maybe, and maybe that's why I feel like that. Um, but I've come to terms with it in some ways and I choose not to think about it in the other ways.*

This comment and others made by Stacey draw attention to several aspects of uncertainty resulting from her history of breast cancer; not only does she face the possibility that cancer may return as it has already done twice, she also considered the uncertainty surrounding why cancer continues to return following treatment. Her suggestion that the breast cancer recurrences have been the result of a self-fulfilling prophecy reflects the uncertain causation and her fears that she is somehow responsible for the cancer, which corresponds to what is reported in a study of women with gynaecologic cancer who pondered similar explanations as a way to make sense of the unpredictability of cancer (Manderson, Markovic, & Quinn 2005). Furthermore, Stacey recognized the lasting impact that breast cancer has had on her life, proposing that cancer has pervaded her life so fully that it will always be a part of her identity. Thus, Stacey sought to manage uncertainty through a combination of various coping strategies including: integrating cancer into her identity, gaining acceptance of her illness history, and denial.

Another young woman who described experiencing a great deal of uncertainty with respect to her illness was Sandra. She expressed that:

*Every time I get sick, I immediately wonder if it's an MS attack, everything, every time I feel odd. So it's weird to have it always there, always present, you can't avoid that... I think the really biggest thing is it's always at the back of my mind, like everything I do is peppered to some degree with this. All the decisions I make, all the thoughts I have, all the choices I make are peppered with it, because there's a lot of 'What-ifs' because that's*



*the nature of the disease, um, you don't know what's going to happen and your mind always jumps to worst-case scenario and so, my worst-case scenario is, you know, not having anyone to take care of me and then being very physically disabled and then incapacitated and stuck in a care home. You know? I don't want any of that, so I do a lot of things with it in my mind. It's never not there.*

Thus, because MS can have a varied trajectory, Sandra was unsure of how quickly her illness might progress or what limitations it could impose. She described the omnipresence of illness in her thoughts and actions, and the preparations that she has made for its possible progression. For example, Sandra talked about the photograph below of the fireplace in her home with respect to the uncertainty of her future with MS and the comfort that the fireplace offers:



*[Illness] was a driving force for us to get this [fireplace] done and it was so much work to get it done and it cost so much money and it took so much time, and it seems like the underlying excuse always was my disease, so 'Just-in-case, just-in-case.' And so finally we got it done and I do love it in ways that I can't explain or I don't feel do it justice enough. Like the peace of mind that comes with hearing it and smelling it and being warmed by it I find so beneficial that, um, like, yeah, I don't know [if it's] disease-specific or not, but it seems like an important part of my life.*

Consequently, Sandra's experience of illness demonstrates how individuals can become immersed in their illness (Charmaz 1991) in that life becomes founded upon illness whether through the management of actual or potential limitations. Nancy was similarly preoccupied with the uncertain implications of illness, and the potentially negative outcomes that surgery and more



drastic treatment for endometriosis could have for her body, relationships, and plans for the future, which will be further discussed in upcoming sections in this chapter.

Melissa had a similar experience of feeling uncertain regarding the impact that illness could have on her future. After the long process involved with gaining a diagnosis, Melissa continued to question whether her diagnosis was accurate and if the natural treatment regimen would contribute to improved health. Despite experiencing relief and hope because of the diagnoses and support obtained from certain alternative health care providers, Melissa illustrated the uncertainty that she continues to face by saying: *I feel it's [an uphill battle] but I feel like once I finally get to the top of that mountain it's going to be fine again. It's just a matter of when and how long.* Thus, she was again in a process of waiting and wondering, but this time it was to see if her health would improve.

These young women's discussions of uncertainty emphasize the ongoing nature of their illness experiences. Although not all participants lived with constant symptoms or signs of their illnesses, the presence of illness was continually felt. For those who had experienced cancer, they described living in a state of liminality (Little et al. 1998) in which they experienced ongoing uncertainty regarding recurrence. Participants with chronic illnesses also reported uncertainty in relation to how illness might progress and to what degree it would affect their lives. The prominence of concerns related to uncertainty resulting from illness is evident in existing literature on individuals affected by cancer (see for example, Gil et al. 2004; McKenzie & Crouch 2004; Nelson 1996; Odo & Potter 2009), as well as those with other types of serious illness (see for example, Charmaz 1991). Although uncertainty is a common experience of our being in the world - our 'fundamental anxiety' (Schutz 1971, cited in Good 1994, p.127) - illness shook these participants' ability to suspend such anxiety as most individuals do on a daily basis.



As such, each of the participants cited above faced a challenge in determining how to continue on with life in spite of a lack of control over disease progression and risk of recurrence. Not knowing what illness entailed also meant that participants were forced to revise how they conceptualized themselves and their future. Specifically, the uncertainty that these participants experienced affected their well being through its effect on their bodies, identities, relationships, and plans for the future.

#### 6.2.2.3 Realizing Mortality

The experience of a life-threatening illness raised significant questions related to mortality and longevity for some of the participants. Specifically, realizations of mortality resulting from illness often introduced anxiety and threatened some participant's expectations for the future. In addition, these participants considered how the possibility of dying from illness would affect their loved ones. Underlying participants' comments are socio-cultural ideals associated with health and illness, the life course, and death. In acknowledging such social constructions, the young women's stories expose the struggle that they face because of the possibility of dying from illness and, further, dying an 'abnormal' death, as most people in industrialized societies have expectations of growing old (Kellehear 2007).

Primarily, some participants recognized the life-threatening nature of the illness by which they were affected. For example, Stacey discussed the realization that occurred following her third diagnosis of breast cancer:

*[My husband and I are] really hoping we're winding it down at this point, that this can be the 'Yes, and then we were done, at thirty-seven, we were done with cancer. It was over.' Um, this is the first time though that it's felt like 'Holy cow, this thing at some*



*point might win.’ ...which I’ve never, ever thought about before because before it was always ‘Well, it’s small enough to cut it out, it’s good to go’ and [the doctors] just move on, and I go back to normal life. This is the first time I’ve taken, um, more than just the period of treatment off from work. Um, this time I’m taking it slow, um, maybe partially because I’m like ‘Hey, this might be my last time. I’m going to, if you can enjoy it, enjoy it’, um, and partly because this time... the cracks are bigger.*

Stacey intimated her hope that her third diagnosis of breast cancer would be her last, but also noted that *this thing at some point might win*. Thus, Stacey referred to having breast cancer as a fight in which she was engaged, drawing upon the commonly used “battle” metaphor (Hunsaker Hawkins 1999). This metaphor endows individuals facing cancer a sense of agency in that they assume an active role in the “fight against cancer” (although how this is accomplished may vary among individuals). The adoption of this metaphor reflects societal beliefs and research that proclaims that actively battling cancer yields better outcomes than submission or acceptance (Ibid). However, Stacey also expressed an awareness of the possibility that she could “lose the battle” (die), thus revealing her awareness of the threat that illness posed to her well being.

Aurelie described a similar awareness of the possibility of death when talking about a friend who had died from multiple brain tumours. She said:

*[People with brain tumours] have a constant reminder that we can die, sooner or later, so, [this woman] was a good friend. I met her [in Canada]. She was treated for thirteen brain tumours and she died just in December and I just learned this in January... it reminds me that death is always possible and is always [hanging over] my head. Or, it’s like my mother says, ‘the Damocles sword’ or something like that.*

Aurelie highlighted her realization that she could also die from her illness as her friend recently had. She recalled her mother’s reference to Damocles’ sword and the suggestion that Aurelie lives in a precarious position in which death could occur at any moment. Aurelie’s comments call attention to the heightened awareness of mortality that results from a cancer diagnosis, as her well being and future are constantly in question. Existing research on individuals with cancer has also identified the increased awareness of mortality that results from such an experience, which



requires the ongoing negotiation of uncertainty (Little et al. 1998; McKenzie & Crouch 2004). Despite her acute awareness of the uncertain future that she faced, Aurelie suggested that optimism was the most significant way for her to cope with the heightened possibility of death. Thus, her comments reflect social discourse that suggests that optimism and good humour are central to the appropriate management of cancer and ill health more generally (Album 1996, cited in Werner, Isaksen & Malterud 2004; McKenzie & Crouch).

Melanie and Leanne also discussed the confrontation of their mortality that resulted from illness. For example, Melanie considered the possibility that death could result from her cancer, which motivated her to pursue further medical testing to ensure that she was cancer-free. Furthermore, recognizing the life-threatening nature of cancer, Melanie indicated that she spends more time with her children and focuses on enjoying life. Other participants, such as Aurelie and Leanne, expressed a similar increased appreciation for life and acceptance of day-to-day concerns. Specifically, Leanne recognized that her life course could have been significantly different as a result of her illness because of her near-death experience, as described in Chapter Four. Due in part to her near-death experience, Leanne expressed a changed perspective toward life that included a more balanced lifestyle and greater focus on enjoying time with family and friends. Thus, the illness experience prompted some of the young women to develop a different perspective toward their lives and the people in them, a transformation that resonates with what has been reported in existing literature on illness experiences (see for example, Kleinman 1988).

Despite that positive growth could result from the realization of mortality, this occurrence led some participants to experience 'biographical disruption' because it required the adjustment of how they envisioned their future (Bury 1982). In particular, Aurelie and Stacey recognized that their lives could potentially be shorter than they had previously expected. Aurelie captured



this experience by commenting that: *You think 'When I am 70... but maybe I won't be 70 at all'... That's difficult because you don't know, your life- is it long or short? It's very uncertain.*

Here, Aurelie highlighted the uncertainty of her future and the recognition that her illness might cut her life shorter than expected. In doing so, Aurelie demonstrated how she has had to re-examine her expectations for the life course as a result of illness and the realization of her mortality. Additionally, she has had to re-construct her identity to account for the possibility that her life may not follow the typical, albeit socially constructed, life course in which individuals live into their 60s, 70s, 80s, and even 90s in industrialized societies.

Similar to Aurelie, Stacey discussed how having cancer has led her to realize the possibility that her life course may not be as long as she previously thought. She stated in respect to the photograph below:



*What going through the cancer journey has done is forced me to confront some of those things or to say to myself, you know, 'Maybe you're not going to be here as long as you thought you were, so maybe you need to seize the opportunities instead of wishing you had done something and then just wishing and never doing it.' And so, um, part of what's in this photo is the store that we purchased which was one of **the** scariest things I have ever done, and I've been having anxiety attacks ever since, um, but it's been good.*



Thus, Stacey also experienced the realization of her mortality as a need to revise how she envisioned her life course. In addition, she suggested that the potential for a shortened life meant that there was a greater urgency for her to realize her goals and dreams, a sentiment that was echoed by Aurelie and will be further discussed in Chapter Seven. Thus, the realization of mortality led these participants to reflect on how they spent their time, focusing on quality of life as individuals affected by cancer often do (Rasmussen & Elverdam 2007). Reference to such an epiphany reflects the common characterization of illness as a ‘quest’ in that insight and personal growth are gained through the illness experience (Frank 1995).

The above quotations demonstrate participants’ cognisance of the threat that illness posed or continues to pose to their well being and longevity. Additionally, their comments show the potential for their lives to be pushed off a perceived ‘normal’ life course because of illness and the possibility of dying earlier than expected. Some participants also expressed a sense of anxiety that an early death could prohibit them from realizing certain aspirations, as was clearly evidenced in Laura’s previously cited comments that contrast her with older women with breast cancer who had already had the opportunity to have children. Thus, the realization of mortality was experienced as a threat to the fulfillment of their envisioned life course, as well as an existential threat. In this sense, these young women experienced the confrontation of mortality differently than individuals facing a life-threatening illness in older adulthood.

In addition to addressing the need to revise their perceptions of the life course, some young women discussed their mortality in relation to their relationships. Specifically, Aurelie, Melissa, and Laura considered the impact that the severity of their illness and the possibility of death had on their loved ones. Aurelie shared concern for her mother’s well being, saying: *My mom is, is... [a mother hen], that means she’s so close to her child because I’m her only child,*



*so, um, she [does everything] for me and, uh, if I die, uh, she will die, or she... It will be really, really difficult for her... for both my parents.* Aurelie believed that the particularly close relationship that she had with her mother would make it very difficult in the event that she were to die from having a brain tumour. Aurelie also indicated that her parents, especially her mother, struggled to accept why her daughter had been affected by a life-threatening illness. Melissa also addressed the concern that she felt for her mother because of her ill health and difficulty obtaining a diagnosis and treatment. Thus, both Aurelie and Melissa considered the impact that a potentially negative outcome to the illness experience could have on their family members.

Similarly, Laura considered the possibility of dying from cancer in respect to her relationship with her husband. Although she expressed feelings of hope, Laura also experienced anxiety over the realization of her mortality and what that could mean for her husband.

Struggling to get the words out, Laura said:

*I know that even if [the cancer] does come back I've still got lots of time left, if and when it does and I'll just, yeah, I don't know. But then there's the other side where I just feel enormous guilt that well, that, um, all of a sudden I'll, I won't, yeah, [my husband] will, sorry... I worry about [him] mostly.*

In making this emotional statement, Laura sought to communicate her effort to be optimistic despite concerns that the possibility of dying from cancer would leave her husband alone. Thus, she viewed the realization of her mortality relationally rather than personally, choosing to focus her fears on the impact that her death would have on her husband rather than herself. Focus on the relational impact of illness may be common for women affected by illness because of the portrayal of women as caregivers in Western discourses of femininity (Stoppard 2000, cited in Lafrance & Stoppard 2006, p.310).

In the above discussion, I describe some of the participants' realizations of mortality that resulted from the illness experience. In addition to bringing about the recognition that illness



threatened their existence, some of the young women spoke of the threat that illness posed to their envisioned life course. Participants such as Aurelie, Stacey and Leanne acknowledged that illness could cause the life course to deviate from the expected and ‘typical’ duration. Thus, in making such references, the young women drew upon socio-cultural beliefs regarding the life course and, specifically, the notion that individuals in industrialized societies will live until old age (Kellehear 2007). Thus, some of the young women recognized that a shorter life meant less time to accomplish their goals and aspirations. As a result, these participants came to view their lives differently, feeling a greater sense of urgency to achieve their goals and enjoy life.

While some participants spoke of the realization of mortality in relation to their well being and imagined future, a few also discussed their mortality in respect to the significant impact that their possible death could have on loved ones. For example, Melissa and Aurelie focused on the emotional burden that their ill health placed on their parents. Their comments broach the idea that death is thought to normally occur at a specific time in life (old age), and that death is ‘premature’ when children die before their parents (Exley & Letherby 2001). Additionally, Laura expressed concern for her husband in the event that she succumbed to cancer, highlighting her fear that her death would bring about great emotional difficulty for her husband. Thus, some of the young women frequently viewed illness in respect to its relational impact, in addition to, or instead of, recognizing the threat that illness posed to their personal well being. As a whole, this sub-theme highlights how illness prompted many of the young women to realize their mortality and the fragility of life. Thus, this sub-theme, along with the preceding sub-themes, provides a basis for the following examination of how participants’ re-negotiated their expectations for young adulthood and the future in light of illness.



### 6.2.3 *Re-negotiating Expectations for Young Adulthood and the Future*

Recognizing that their lives would be forever changed because of serious illness, participants were involved in a process of re-negotiating their expectations for young adulthood and the future. Disruptions in everyday life and short term plans as a result of illness contributed to further disruptions in long term plans or setbacks in the achievement of certain tasks or aspirations. As such, many of the participants were required to revise what they envisioned young adulthood and the future to be like. However, this re-negotiation of expectations was problematic because it involved trying to come to terms with uncertainty and losses or potential losses resulting from the illness experience. Thus, in the following paragraphs, I elaborate on participants' struggle to manage their expectations in light of illness.

Given the duration of Stacey's illness experience when I interviewed her, she was able to most articulately communicate the disruptions to her expectations for young adulthood that illness had brought about. Stacey captured the rupture between what she expected her 30s to be like and what they had turned out to be like by saying:

*I feel like [my husband and I have] fallen behind, and maybe that's ridiculous, but when I entered my 30s I remember sort of what my unwritten list of goals were for, you know, by the time I'm 40 these are the things that I'm hoping we've accomplished, you know 'I wanna have the mortgage paid off, we will have kids...'*

She explained how she and her husband had failed to accomplish some of the things that couples often do in their 30s because they had put life on *pause* for her illness. Her comments highlight her awareness of the life events typically associated with young adulthood, such as establishing a career, gaining financial stability, having children, and setting up a home. As mentioned previously, Stacey experienced her diagnosis as particularly disruptive to her career. Laura also discussed many of the same issues, noting that her breast cancer diagnosis led to setbacks in the



completion of her education, obtainment of a full time job, and buying a home with her partner, which had financial ramifications. Thus, Laura and Stacey continued to negotiate their current situations with respect to their expectations for this time of their lives.

One expectation for this time of life that many participants talked about at length was having children. Describing her 30s, Stacey recalled:

*There's this big gap in which I've learned a lot and grown a lot and met a ton of people, but have not done some of the things that people normally do in their 30s and, at this point, we may never because of [the cancer], um, and one of the most important parts of that is planning a family, which you can't do while you are going through this process because your body won't do it, where it's so full of chemicals that you couldn't responsibly do that and you can't come off the medications until a certain time frame when they're hoping that you'll be okay.*

She also noted that her and her husband had taken steps to start a family previously by ceasing hormone therapy, but unfortunately more signs of breast cancer were discovered soon after. Thus, her desire to become a parent had gone unfulfilled as of yet because of multiple breast cancer occurrences and ongoing treatments.

Nicole and Laura shared similar sentiments related to the desire to have children during their young adult years. For many of the young women, their physical ability to bear children was compromised by illness or the medication that they were required to take. For example, Nicole described her expectations for having children and the uncertainty introduced by illness:

*The last time I saw [the doctors], they said 'Well, we'll have to see but you'll probably have to take it for a couple more years.' and I'm like 'No, I just don't want to have to take it for the rest of my life.' 'cause... they don't know about birth defects, or what effects, and I don't really want to take it much longer 'cause I do want to get married in the next couple of years and, and start my family.*

Laura also shared the experience of not knowing if she would be able to have children, as this would not be determined until after the completion of five years of hormone therapy.



Recognizing this potential loss, she said: *I don't know, I don't think I've dealt with it fully yet because I don't know yet if, which way it's going to go, but it's kind of just trying to prepare myself for both eventualities.* Both Nicole and Laura's comments highlight how their expectations were threatened by the possibility that their ability to have children was compromised by illness or its treatment. Other participants, including Nancy and Sandra, also shared similar thoughts regarding possible complications imposed by illness with respect to fertility and pregnancy. While concerns about fertility and pregnancy with respect to illness have been well documented in young women affected by cancer (Coyne & Borbasi 2006-7; Dunn & Steginga 2000; Grinyer 2007; Odo & Potter 2009; Lynam 1995), further research is needed to ascertain the extent to which young women affected by other types of serious illness experience this set of issues.

Participants also talked about their education and employment goals, and how being ill had affected them. In some cases, illness forced participants to take time off from university or hindered their ability to secure desired employment, as was the case for Aurelie and Laura respectively. As mentioned in Chapter Five, Leanne was also required to take a leave from her education as a result of her hospitalization and period of recovery from anorexia. She described how she has had to adjust her expectations of herself with respect to her studies: *[Before] I was the person that was gonna have their master's by 25, was gonna have their thesis done, like I was gonna be done. But now I'm like 'I'll be done when I'm done.'* This quotation from Leanne demonstrates how illness caused a significant disruption to her educational attainment and envisioned life course.

Melissa also spoke about her goals in a similar way as Leanne, indicating how she had relaxed her expectations for herself somewhat since becoming ill:



*It's just a matter of making adjustments, um, you know? At first I thought 'Oh maybe I'll do an Honours program.' and then I realized that I don't need to push myself, or force myself into getting those grades that I know would be achievable if I wasn't sick. But I can only do what I can do right now and I don't want to put my life on hold any longer... In the first year [of university], I was putting the pressure on myself but after realizing I just can't do it, the best thing I can do is not put pressure on myself and not worry about that. So I don't know, um, if, for me it's a matter of how things are going to be, you know, in a year or two from now... I don't put any expectations on myself.*

This quotation demonstrates the tension between Melissa's prior expectations and her revised outlook due to illness; specifically, Melissa continued to have hope for the achievement of her goals and dreams, but also put less pressure on herself. Charmaz (1991) reported such an occurrence as common among the chronically ill, finding that "illness and disability force lowering expectations of self – at least for awhile" (p.21). However, despite confronting the likelihood that certain goals may go unachieved, Leanne and Melissa continued to strive for certain goals or achieve them in partial ways. Thus, having to take time off from university or trying to negotiate academic or work responsibilities while being ill may pose problems for young adults and necessitate that they re-negotiate expectations for this life stage.

Finally, while many of the changes that participants talked about with respect to their expectations were relatively negative, a few participants discussed new expectations for young adulthood and the future in positive terms. Elizabeth, for instance, described feeling a greater purpose in life following her recovery from depression. Specifically, she indicated that she may pursue education and employment related to alternative therapies. Melanie also had initiated a new career path since her breast cancer diagnosis. While she had considered entering the nursing profession previously, she believed that experiencing breast cancer affirmed her decision to pursue a nursing degree and endowed her with invaluable life experience that could help her to empathize with patients. Thus, these participants' experiences demonstrate the transformative aspect of illness for some individuals (Kleinman 1988).



This theme illustrates how many participants' past visions of their future were threatened by illness, forcing them to re-negotiate their expectations and acknowledge that previously held dreams may be delayed or go unfulfilled. For example, some of the young women experienced illness as a disruption to the achievement of tasks and goals common to young adulthood, such as obtaining an education, securing employment, establishing a home, gaining financial stability, and having children. While some participants experienced setbacks in these respects, other participants did not yet know if their goals and dreams would be achievable in the future or not. Specifically, the uncertainty of fertility and the impact of medications on foetal development were identified as potential contributors to the loss of opportunity to have children. Thus, participants were required to re-negotiate their expectations in order to account for potential losses, which often involved revising components of their self identity. However, re-negotiating expectations for young adulthood and the future did not always involve losses, but also included relaxing expectations that they placed on themselves or pursuing a new path in life.

#### *6.2.4 Summary*

The above discussion highlights several ways that the young women in this study experienced illness as disruptive to the life course. Foremost, many of the participants described being ill during this time of life as making them feel abnormal or “off time” (B.R. Williams 2004), referring to the belief that their illness moved them off a life course typical in Western societies. Specifically, many of the participants compared themselves to people their own age, resulting in the recognition of their divergence from the typical social roles and activities of young adulthood. In some cases, participants were faced with bodily experiences that were more



common to younger or older individuals, which threatened their young adult identity. Further, some participants compared themselves to other individuals affected by the same illness, noting that they had little in common besides illness. However, it is important to note that some participants found interactions with individuals of various ages affected by the same illness to be supportive, which will be discussed further in the following section on relationships and support.

In addition to feeling abnormal and “off time”, participants discussed the need to manage their well being with respect to the threats introduced by illness. Participants expressed feelings of vulnerability and a shift in the way that they saw themselves. Foremost, some of the young women spoke about realizations related to their independence and perceptions of control, acknowledging that illness prompted them to become aware that they possessed little control over life. The uncertainty faced by several of the participants compounded feelings of vulnerability, as participants continued to struggle with fears of recurrence or the unknown progression and implications of illness. Furthermore, some participants were confronted with their mortality, leading to the recognition of the possibility of dying from illness and the implications that this would have for loved ones. As a result of the threats to well being that illness posed, many of the young women were forced to revise their sense of identity and accept that their life may not unfold in the way that they had formerly envisioned, which was sometimes positive as well as negative.

Part of the process of managing the disruption that illness caused to participants’ life course involved re-negotiating their expectations for young adulthood and the future. This re-negotiation was both something that had previously occurred and was in the process of occurring. For example, some participants noted how young adulthood had turned out to be unlike they previously expected, while others discussed how the near future may turn out



differently than they had hoped because of illness. Many of the participants specifically focused on the desire to have children and the barriers posed to realizing this goal by illness and its treatment. Although the majority of participants highlighted fertility and pregnancy as concerns, Aurelie indicated that she did not wish to have children, while Elizabeth did not address this issue in her interviews. Other goals that required re-negotiation were related to education and career, with some participants explicitly stating that they no longer had as high expectations of themselves as before.

Overall, the three sub-themes described in this section highlight how illness was disruptive to their young adult lives and the fulfillment of their envisioned life course trajectory. Specifically, illness interrupted participants' movement through the life course, causing them to feel different than other young adults. In addition, illness threatened psychological and emotional well being because of the losses or potential losses that it brought about, many of which were related to social roles common to young adulthood. Thus, while participants shared concerns common to other individuals with serious illnesses that have been identified in existing research, such as uncertainty and mortality, they understood these concerns in respect to their inconsistency with expectations for young adulthood and the life course. In the following theme, I explore the implications that illness had for the young women's relationships and the acquisition of social support.

### **6.3 Managing Relationships and Social Support with Respect to Illness**

In this theme, I explore participants' discussions of the negotiation of support & relationships with family members, partners, friends, and similar others during the illness



experience. Some of the young women relied on family for physical, emotional, instrumental, informational, and financial support, while others turned to partners, friends, or support organizations. Many of the young women expressed an overall appreciation of the care and support that they had received from multiple individuals, and emphasized the role of others in the coping process. However, participants also resented that illness introduced worries into the lives of others and often changed their relationships with family members, partners, and friends. Thus, the young women faced the negotiation of complex relationship issues amidst their own efforts to cope with illness. Participants also discussed the perceived importance of similar others with whom they could share their experiences and concerns about illness. While some participants found such similar others, some of the other young women identified a lack of similar others and thus a lack of such peer support. In the following sub-themes, I elaborate on participants' comments on relationships with family members, partners, and friends, as well as support from similar others, in order to demonstrate how social support from other individuals was managed during the illness experience.

### *6.3.1 Relationships with Family Members*

In the following paragraphs, I examine the young women's reflections on their relationships with family members during the illness experience. Many of the young women described the social support received from family members and told stories of their love and assistance. The value of family members during times of illness has been widely documented, with family members often being key resources and sources of social support for ill individuals (see for example, Kyngas et al. 2001; Lynam 1995; Pierret 2003, p.13; Steinglass 2000, p.6).



Participants recognized that their being ill had a significant impact on their family members, and many experienced anxiety about the burden that they had introduced into their family's lives. In addition, some participants described relationships with family members as sometimes problematic, which added an unwanted burden to the coping process. In such instances, participants sought the support of other individuals in their social network, which will also be discussed in the following section.

In general, all of the participants noted the importance of family in offering various forms of support during the illness experience, including: emotional, financial, instrumental, and informational support. Several of the participants chose to demonstrate family members' involvement or significance to the coping process by including them in their photovoice project. For example, Aurelie used this pre-existing photograph of her parents to talk about her family:



*So my parents are a good support and my family, I just have a picture of my parents, but all my family are a support, and it reminds us that family is the best support we can have even if they are far away from us... My grandmother cried when she saw me, and all my*

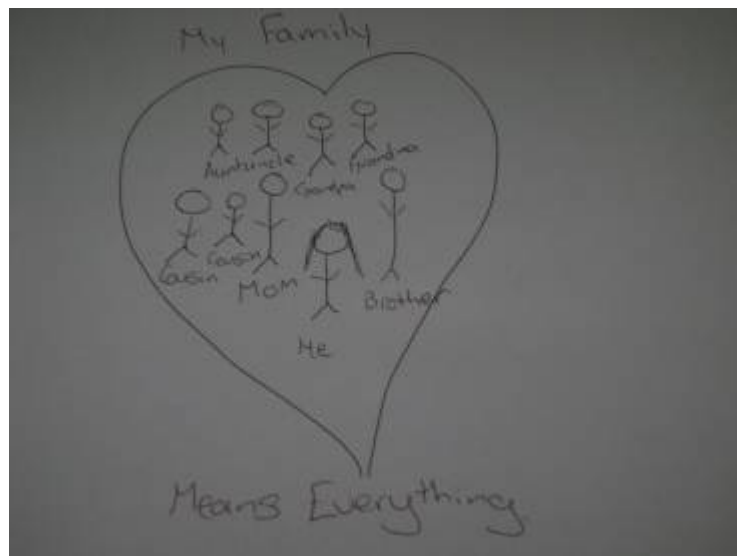


*family, a cousin that I haven't seen for 8 years, I saw her and [my illness] makes the family stronger and closer, so it's bad and good.*

Such an expression speaks to the overall support that Aurelie received from her family members, all of whom lived on a different continent. She indicated that her relationships with family members were strengthened as a result of her becoming ill, which she viewed as a positive outcome of her experience.

Leanne also expressed a sense of appreciation and love for her family members, whom she captured in the drawing depicted in the photograph below. Leanne explained:

*I didn't want to get a[n individual] picture of, like, every single member of my family. Because I couldn't, I just kind of drew a picture of my family. So it's me, my brother and my mom, my grandparents, my one aunt and my one uncle, and then my two cousins... Even though like my grandparents and my aunt and uncle don't live with us, I still consider them my immediate family. They're the ones who were with me throughout the entire process. They never, um, left, you know? They visited me in the hospital, they [were] always encouraging me when I was really, really sick and ...they stood by me. They didn't desert me. And I had friends, so-called friends, who did, so it just kind of solidified the importance of family to me and how extremely, extremely important they are to me now and were to me through my sickness.*



Leanne described how her family members had supported her recovery through their presence and words of encouragement. She placed emphasis on the belief that she was able to rely on



family, which was not necessarily the case with friends. Leanne's comments reflect the findings of a study of family support for young adults with cancer in which "physical presence, tangible actions and an 'unquestioned understanding'" were identified as the basis of family members' caring and support (Lynam 1995). Thus, her family members' willingness to stand by her during the illness experience revealed the importance of family to Leanne.

The importance of unconditional love from family members, which Leanne referred to in the quotation above, was often discussed by the young women. Participants observed their family's love through their involvement in medical appointments, gathering information, listening, or negotiating the health care system. Simply being together was also thought to be a significant way that care and support were offered, as evidenced in Laura's comment:

*I'd had a mammogram and we were pretty sure [that it was cancer] but, and actually that weekend while I was waiting, there was, um, [a fundraiser for cancer research] in my hometown... My dad had just been diagnosed [with prostate cancer] I think it was the year before so we were all going to do that and so, yeah it was kind of a good weekend. I don't know, I got to spend it with my family.*

Although not all participants who talked about family relationships noted an increased sense of closeness, it was evident that the illness experience frequently contributed to closer relationships or affirmed already close relationships, as was also found in a study of young people with cancer (Kyngas et al. 2001).

Interestingly, the impact of chronic illness on young adults' relationships with family members has gone unexamined in the existing literature compared to young adults with acute or life-threatening illnesses (although existing research suggests that young women with eating disorders may isolate themselves from family members because of the 'secretive' nature of such illnesses (Broussard 2005)). Correspondingly, the participants in this study who had a life-threatening illness or came close to dying described increased closeness in some family



relationships more often than those with less acute or chronic illnesses. This observation suggests that the perceived severity of illness may influence how family relationships are affected by illness, particularly over the long term. For example, Sandra noted that her sister showed compassion to her situation when she experienced her second MS episode; however, Sandra reported that this compassion had not continued and her relationship with her sister had since returned to its previously tenuous state. Nonetheless, further exploration of the impact of chronic illness on family relationships is required in order to clarify differences among various illnesses.

As discussed in Chapter Five, some participants found themselves in a more dependent relationship with family members than previously. For example, Aurelie's mother came to Canada to live with and care for her during treatment. Elizabeth and Melissa, both of whom lived with their sisters, reported depending on their siblings for instrumental support. Similar to these participants, Leanne also talked about the shift that had occurred in her relationships with family members during her hospitalization and recovery:

*Last year, [my family] had to take care of me so I was like a child again. So they were worried about me and they were angry with me, but I was a child 'cause I was so dependent. Now I'm back to being that 25 year old woman with, you know, more of a, like with my mom it's more of a friendship relationship now. And like with my grandparents, I'm the older granddaughter. I'm not the child anymore.*

Leanne indicated that being ill changed her relationships with family members by casting her in a dependent role. However, Leanne also suggested that she had shifted away from this dependency on family members since her recovery, thus re-gaining much of the reciprocity that was present in these relationships prior to her becoming ill. Nonetheless, Leanne also indicated that her mother continues to have concerns about the possibility of her becoming ill again.

The cause for concern that illness raised in parents was discussed at length by several other participants. Specifically, Nicole and Aurelie were faced with the idea that their illness had



introduced worries into the lives of their parents. Similar to Aurelie's comments cited earlier in this chapter, Nicole stated:

*I'm an only child so when my parents had to watch me go through brain surgery I was like 'I never want to do that to them again.' because it was really hard on them, and then here I am in the hospital again and I'm like 'Oh great.' Like it wasn't so much that I was upset, I was upset for them 'cause I'm like 'I don't like them having to see me go through this and it upsets them.' ... I think my parents were worried that I was going to get some sort of, like, almost like, sentence, that this was what my life was gonna be like and everything was gonna change for me.*

Here, Nicole communicated her concern over the worries that her surgery and epilepsy diagnosis raised in her parents. She noted that it was particularly difficult for her to watch her parents' reaction to her diagnosis while she remained optimistic that illness would not limit her. Aurelie expressed similar thoughts regarding her parents' struggle to deal with her diagnosis, indicating specifically that her mother experienced guilt because she believed that she was somehow responsible for the brain tumour. The difficulty experienced by these parents in coping with their daughters' diagnoses sheds light on the difficulty that can arise when children become ill or die before their parents, specifically because such occurrences are viewed as 'out of order' or inconsistent with expectations for the life course (Exley & Letherby 2001; Miedema et al. 2007). As such, both Aurelie and Nicole sought to assure their parents that they did not perceive illness as a barrier to a fulfilling life.

Melanie also talked about having to manage how she disclosed to her mother that she had been diagnosed with breast cancer. As described in Chapter Four, Melanie hesitated telling her mother because of the hardship that she had already endured because of other family members' cancer experiences; however, Melanie disclosed her diagnosis to her mother, which was received with many tears. In response to her mother's emotional reaction, Melanie remembered reassuring her mother that she would survive, which was pivotal in assisting her mother with coping. Thus,



despite her mother's initial emotional response, she was a major source of support for Melanie and her family, taking her to and from appointments and surgeries and helping to care for her children. Melanie, Nicole, and Aurelie's experiences, as well as those of other participants, highlight the need for young adults to negotiate the impact of their illness on family members, an issue that has also been highlighted in the literature on young adults with cancer (Hilton et al. 2009; Lynam 1995); specifically, young adults may be required to offer support to family members amidst their own attempts to cope with illness.

As a result of the distress that parents experienced due to their child's illness, some young adults reported problematic aspects of their relationships with parents. Two of the young women affected by breast cancer, Stacey and Laura, indicated that their parents had not always been helpful to them during the illness experience. Stacey elaborated that:

*The only relationship that really has suffered, um, but maybe it was always going to suffer, is, um, I have a very odd relationship with my parents and... I know they're going through their own thing, um, but they can often be a burden on me, especially in the critical times where I don't have any energy to be their support, they need to find it elsewhere, um, but any attempts that [my husband] and I have made or that my siblings have made to get them help have been met with such resistance that we've given up trying. So it's made me have to figure out a way to have them in my life but not get angry all the time which, you know, is a tippy thing. But so many times I've said to myself 'It'd be so awesome to just be able to call my mother right now and say "I need you to come because I can't clean the house and I can't cook the meals and I need just to be taken care of."' But she's not available to me in those ways, and when they do come she doesn't help... It took a while to give up the 'What am I supposed to do to make this better for them?' because I finally just said to myself 'You know what, right now I'm the patient, and they have to figure that out or not figure it out and I can't go there 'cause it's too draining.'*

Here, Stacey emphasized that her parents were not always supportive during her illness experience because of their own difficulty in coping with her being ill, which has been burdensome to her coping process in the past. According to Lynam (1995), young adults with cancer may find themselves in contradictory roles in which they require support from family



members but also need to offer support to them at the same time, which requires mutuality to be established. However, in Stacey's case, her parents were not emotionally able to deal with the possible implications of her being ill and thus a mutually supportive relationship did not exist.

Laura also reported that her mother had not provided adequate support to her after being diagnosed with breast cancer. She recalled a specific example by saying:

*It was interesting to me that after my surgery my mom came and stayed with us and I needed help. I had Homecare come in and help with, uh, dressing changes, but one day I needed [the] dressing changed in between dressing changes and it was [my husband] that helped me... My mom was like 'I'm sorry, I'd passed out, I can't, I can't do it'... I understand... but now I guess I'm maybe a little bit mad about that actually.*

Although she had managed without her mother's assistance at the time, Laura described being resentful that her mother had not been able to meet her care needs. She also indicated that she found it difficult to communicate with her mother during that time, which she attributed partly to her mother's feelings of guilt that her daughter had been diagnosed with breast cancer at such a young age. Underlying Stacey and Laura's comments, as well as those cited above from Aurelie's interviews, are references to socio-cultural expectations regarding familial roles and care giving. Namely, these young women's parents appeared to have difficulty coping with their daughters becoming ill 'out of order', while mothers may also have felt as if their child's diagnosis was reflective of their failure to be a good mother and ensure their child's health.

Some parents' inability to care and support their daughter in the ways that they required seemed to threaten these participants' views of their mothers as the caretaker of the family. As such, some participants turned to their partners, siblings and/or friends for care and support. Stacey, for example, talked at length about the valuable support that she had received from her sister, brother, and sister-in-law, and included a number of photographs of them and their



children in the study. Stacey talked about the following photograph to highlight some of the ways that her sister in particular had supported her:

*So that's my sister and her little girl and me, and... My sister has just been amazing about involving me in [my niece's] life [because I haven't been able to have children]... And the whole journey I guess really involves my sister too from the fact that now she has this worry 'cause now we have a family history and, um, she's going through this process as well and, and both [of us are] dealing with the fact that [our] mom has kind of checked out and so we're kind of the mom to each other.*



Stacey drew attention to how her sister is deeply involved in her illness experience, noting that her support has been crucial given the challenging relationship that she has with her parents. Furthermore, her sister, brother and sister-in-law's willingness to include Stacey and her husband in their children's lives was greatly appreciated, as was their ability to listen and offer support.

Nancy also struggled because of the lack of compassion that she encountered from her mother as she continued to negotiate the symptoms of endometriosis. Although some communication with her mother regarding illness had occurred, Nancy reported difficulties in obtaining adequate support from her mother. When I asked Nancy during the second interview if she had spoken any further with her mother (who had also had endometriosis), she replied:



*We don't really talk about it. She gave me some money to help me pay for all of [the prescriptions] but that was it. And I told her, I said, like my dad came into the room as we were talking about it and he's like 'Oh, what are you guys talking about?' My mom's like 'Nothing.' You know? And like I told her after, I was like 'Kay, it makes me feel really bad when I have this problem and then we can't even talk about it, it makes it seem like it, it just makes it seem like that much more worse.' So, and she's just like 'Oh, well, your father just gets upset by these things, that he can't do anything, you know. He was upset when I had it.' And it goes back to that 'When I had this'-type dialogue. And it's just like 'Well, okay.' And then, yeah, she gave me some money. And then yeah, there hasn't been much discussion about it. I can probably call her and tell her what's going on but I don't know.*

Thus, Nancy perceived her mother as being emotionally unsupportive because attempts to talk about her experience of endometriosis were met with a focus on her mother's past experience of the illness, rather than the opportunity for Nancy to discuss the issues that she was facing. As such, Nancy turned to her partner and friends to fulfill some of her support needs, while others were left unmet. However, Nancy also acknowledged that her mother was supportive in offering her money to cover the costs of her medications. Other participants, including Leanne and Elizabeth, also reported receiving financial support from family members during the illness experience.

As discussed earlier, some participants were reliant on family members at certain times during their illness experience. For example, Melissa relied on her sister to drive her places and for performing housework, whereas Leanne relied on her mother, brother, or grandfather to drive her places while she recovered the strength lost due to anorexia. Elizabeth talked about the limitations that were introduced by her illness and how her sister was pivotal in ensuring that she was taken care of during that time. In particular, Elizabeth lacked motivation to participate in many of her everyday activities because of the depression from which she was suffering, including cooking and cleaning. However, despite her sister's instrumental support, Elizabeth



described a general lack of understanding of what she was going through by her sister, which she illustrated with the following story and photograph:

*My sister was still at university at that point and, and so we were roommates for the first time... and honestly I don't think I saw quite as much compassion from [her and her partner]... Not that their support wouldn't be there, but I think that they of all people maybe didn't understand it... I'll tell another story, academically, um, this was after I was prescribed the medication, um, but I, I had an English essay that I had done and failed it. It was the first [assignment] I'd ever failed, you know, and, um, not surprising really, I had just gotten it done, whatever... I got this back and, and I was just feeling very bad about it and I was at home washing potatoes over the sink and I remember I told my sister this, you know, and her response was like 'Elizabeth', you know, like, kind of a pep talk, like 'You can do it, you know, like or just next time!' [And] like just tips about how to do [essays] and I just, I knew she meant well but that wasn't helping at the time at all, you know? I wanted her to understand - I knew this was direct[ly] from the illness... My brain, you know, wasn't the same I guess. So I think it kind of bothered me in a way and I started crying and I said to her, I looked at her and I said, you know, like 'You don't understand, like you don't get it. Like the fact that I can cry right now is progress.' Trying to bring home like it's not, this isn't a normal situation for me, right now.*



Thus, while Elizabeth's sister had provided important support in some ways, she was not compassionate to the implications of having depression for Elizabeth's educational attainment. Elizabeth's recollections demonstrate how relationships with siblings were dynamic during the illness experience, which was also noted by Sandra.



The experiences of participants discussed above reveal how relationships with family members can be both positive and negative for young adults during times of illness. In many cases, bonds with family members were solidified or intensified as a result of the illness experience, as has been observed elsewhere (Kyngas et al. 2001). However, while several participants described overwhelming care and support from family members, it was evident that variation existed among participants and often depended on the history of their family relationships, as has been noted by Lynam (1995) and Miedema et al. (2007). Parents were sometimes unable to provide compassionate support to their daughters and, consequently, some participants turned to partners, siblings, and/or friends for their unfulfilled support needs. As well, a few participants discussed siblings' seeming lack of understanding of the illness experience at times, although this varied. These findings confirm that "shared experiences and common understandings" contribute to supportive interactions (Gottlieb 1981; Lynam 1987, cited in Lynam 1995), while not attempting to empathize with the ill individual produced unsupportive interactions between participants and their family members.

Several young women perceived a need to manage the concerns of their parents alongside their own worries about the ramifications of illness, which has been previously reported in a study of young adults with cancer (Lynam 1995). It was repeatedly brought up by most of the young women that they felt guilty about the worries that they had introduced into their family members' lives. As a result, some young women tried to take on supportive roles, however this was sometimes too stressful amidst their own coping process. These findings indicate the essentialness of support services for families of young adults with serious illnesses who are having difficulty coping, which can ensure that young adults are not over-burdened by the need to support family members while also managing their own coping efforts. Additionally, given the



complex issues that arise for young adults affected by serious illness due to their life stage, health care and support providers should not assume family relationships and parent-child relationships in particular to be positive or supportive as this could leave young adults with unfulfilled needs. Further, the negotiation of support with family members may be further complicated by the presence of a long term partner, as illness can introduce a number of complex relationship issues that will be discussed in the following sub-theme.

### *6.3.2 Relationships with Partners or Potential Partners*

In this sub-theme, I examine the experiences of some participants of negotiating a relationship with an intimate partner in respect to illness. For the most part, these participants focused on the valuable care and support that they had received from their partners. However, the young women also talked about the feelings that resulted from the potential implications of illness for their relationship, and significant relationship issues that arose because of illness. In addition, I conclude this sub-theme with a discussion of three participants' thoughts on dating and the need to manage the disclosure of illness. In identifying this sub-theme, I elucidate the effects of a serious illness diagnosis on these young women's relationships with partners and potential partners, as well as specific relationship issues relevant to young adulthood.

Foremost, participants who had long term partners talked about the care and support that they had received at the time of their diagnosis and since. Laura indicated that her fiancé at the time of diagnosis, now her husband, was her major source of support during the illness experience because she did not have family in the city where she lived. She described how he accompanied her to medical appointments, cared for her after surgery, watched television with



her when she had insomnia, and shaved her head for her during chemotherapy. Nicole expressed a similar sense of appreciation for her boyfriend, who she described by saying: *He's been there for me through everything. He's kind of been the one I turned to when I was scared and, I don't know, I guess my rock through the epilepsy and the [brain] surgery and everything.* Such comments highlight the comfort offered by these young women's partners amidst the unpredictability that illness introduced to their lives.

Similar to Laura and Nicole, Stacey and Melanie also drew attention to the critical support offered by partners, particularly in respect to the uncertainty and physical changes resulting from breast cancer. Stacey described her husband, whom she was dating at the time of her first diagnosis and had married in between her second and third diagnoses of breast cancer, saying:



*[My husband] is an amazing support, um, he doesn't rattle easily and he's got a great sense of humour and when I wanna just lay down and pout, he's right there behind me saying 'Well, take what time you need to rest but the pouting's not cool, so you need to get over that.' You know what I mean? Um, or he will look at, this time, right from day one in the hospital when the dressings came off, he's right in there saying 'Oh well, yeah, that's pretty ugly but it doesn't bug me.'*



Stacey's description of her husband highlights the role that he has played in her coping process by offering optimism during her low moments and reassurance that his love transcends her physical appearance. Melanie shared similar thoughts regarding her husband, saying: *I've found that [this experience has] brought us closer together, like him saying, you know, like 'You're still beautiful. They're only breasts, don't worry about it. Let's just worry about you and get everything taken care of.'* Thus, these participants emphasized that their partners were important sources of emotional support regarding the physical changes and limitations resulting from illness, and had offered a sense of stability during times of uncertainty.

Despite that none of the participants who were in long term relationships with partners reported negative outcomes due to illness at the time of their interviews, these young women broached certain illness-related issues that had arisen in their relationships. For example, Laura and Nicole both indicated that they experienced guilt because of the worries that they had introduced into their relationships. Laura appeared to be plagued by feelings of guilt and the disruption that her having breast cancer had caused to her husband's life. As mentioned previously, she was particularly anxious about the possibility of dying from breast cancer and the implications that that would have for her husband. Nicole also discussed how guilt about having a serious illness led her to question her relationship with her boyfriend. She recalled:

*I always said to him 'Well, don't you want to be with someone who's not sick?' 'cause I was pretty sick there for a bit with the surgery and the seizure... He thought we should be together. But I just said, you know, 'Down the road if we have kids and stuff you'll want someone you know who is going to be healthy or has a better chance of being healthy?' 'cause now I'm, you know, sick... But [my being ill] has made [our relationship] a lot better [because] I think it kind of showed us we can last through certain things, so it's a good kind of test.*



In saying this, Nicole communicated her initial belief that her ill status made her a less appealing partner, a sentiment that Nancy also shared. However, Nicole indicated that her boyfriend had expressed his commitment to her, showing his caring and the strength of their relationship. Thus, the experiences described by Laura, Nicole, and Nancy indicate that feelings of guilt and doubt may arise in intimate relationships as a result of illness, whether or not they are warranted.

Issues related to fertility and having children were also prominent for some of the young women and their partners. As noted earlier, Nicole worried about the effects of medication and the limitations of illness on having and raising children, and how this would impact her relationship with her boyfriend. Laura also talked frequently about fertility issues, stating that she was currently waiting to see whether her and her husband would be able to conceive following the completion of her breast cancer treatment. She indicated that she was considering the possibility of adoption in the event that she could not have children, an option that she believed her husband was not receptive to. Thus, the possibility of not being able to have a biological child was viewed by these participants as potentially damaging to their relationships with partners, although neither had encountered this specific issue at the time of the interviews.

Nancy expressed that the threat that endometriosis posed to her fertility had significant implications for her relationship with her partner. In the following quotation, Nancy highlighted the uncertainty that she faced with respect to her fertility and the need to address this issue with her relatively new boyfriend:

*I don't know what [the uterine lining is] on, like where it has escaped to, like the lining? I thought I had a bladder infection so that gives me clues that maybe it's on there. But, if it's on my ovary or fallopian tube at all, man! Like, that seriously puts my fertility at risk, you know? So then 'Am I ever going to have kids?' 'I don't know.' So then [my partner and I] had to have this discussion of like, 'Okay, so if I ever do go in for surgery like what should I tell them?' ...It was really hard to deal with. Like, we hadn't really talked*



*about having kids until that point. But then like we were kind of like forced to 'cause we haven't been, well, we've been together for a year, but like, you know, not very many people are planning on having kids at our age, after only being with someone for a year. So we were having conversations that we weren't really prepared to have. But that's like, a big 'if'. You know, like if I ever go in for surgery.*

Here, Nancy indicated that she felt *forced* to broach the issue of having children with her boyfriend of one year along with the potential implications of endometriosis. Thus, Nancy found herself in a complex situation in which she was facing uncertainty on two fronts: with respect to possible infertility, and the potential impact that this could have on her relationship. Stacey also recalled that her first breast cancer diagnosis had raised issues related to fertility that her and her partner were not ready to deal with at that time. These two participants' experiences suggest that young women in newer partnerships may require support in negotiating issues related to fertility and pregnancy that may be previously un-discussed.

Another relationship issue that was raised by a few participants was related to intimacy. For example, Nancy indicated that the side effects of her illness had been detrimental to her and her partner's intimacy. Specifically, the excessive bleeding and pain posed physical barriers to sexual relations, while the mood swings that she experienced strained their emotional relationship. Laura also shared similar thoughts, saying: *Intimacy and sexuality, it's a huge problem. Just, yeah, menopause is not good times. Just, like [my] libido is non-existent and all the things that go along with that. It's, yeah, it sucks. It is very challenging.* Here, Laura described the menopausal symptoms that she experienced as a side effect of treatment as detrimental to intimate relations with her partner, an issue that has been reported in research on younger breast cancer survivors (Walsh et al. 2005). Further, as noted in Chapter Five, a changed relationship with her remaining breast had also altered Laura's sense of her sexuality. Thus, these



two participants' comments call attention to how both physical and psychological factors can affect intimate relationships with partners for young women with serious illnesses.

While Melanie shared similar concerns to Laura regarding body image, her primary focus was on how her being ill affected her husband and children. For instance, she described how her and her husband had to negotiate the care of their children along with her own care following the mastectomy and reconstruction surgeries that she underwent. As such, Melanie recognized that illness is not experienced individually but has implications for the whole family, as has been reported by other mothers affected by breast cancer (Fitch et al. 1999). She recalled in relation to this photograph:

*You're sitting there talking with your social worker and she's asking how you are and how everything's going and all that kind of stuff, and all you're sitting there thinking in the back of your mind [is] 'How are my kids today?', 'How's daycare going?', 'How's this going?' You know, they focus on you instead of other parts of your life. Because I'm sure that, you know, talking to the kids would help too. Having, talking to [my husband] would have helped instead of just talking to myself, 'cause I know that, you know, it's not really, you know, conducive to just talk to the one part of family when it affects the whole family.*



Melanie emphasized the need for support by all members of the family, as they were also significantly affected by the illness experience. Specifically, she recalled worrying about how her



husband was managing the stress of her being ill, especially given her daughter's premature birth shortly before Melanie's diagnosis. As well, Melanie considered issues regarding how changes in her role as a mother might affect her children and the best way to talk to her three year old son about illness, an issue common for mothers with breast cancer (Ibid). Thus, Melanie faced some unique issues in relation to her relationship with her partner because they had young children.

The above discussion addresses five participants' experiences of care and support from partners during the illness experience, and the need to manage various implications of illness for intimate partner relationships. In addition, three other participants discussed what it was like to negotiate their ill status or history of illness with respect to dating. Specifically, these young women wondered about how they would disclose to potential partners that they had been affected by a serious illness. For example, Leanne said: *One thing I've kind of wondered about myself is relationships, like I haven't had a relationship since... [My last relationship] was like way back... So I always ask myself like 'What do I tell?' I don't know yet. I think it'll depend on the person.* Sandra pondered a similar concern, stating: *I've often wondered at what point do you tell somebody that you have [MS], if it's someone you don't know? At what point, and then how do you say it? Of course some of these books have tips on that, but I haven't been dating... so I haven't had to deal with it yet.* Thus, both Leanne and Sandra related that they questioned how to disclose their ill status/history of illness if they were to date, but that they had not yet encountered this issue. However, these two participants also faced distinct situations related to disclosure and illness; Leanne had recovered from anorexia but continued to negotiate the possibility of a relapse and the stigma associated with mental illness, while Sandra had experienced a couple of MS episodes and was otherwise healthy, but faced a more unpredictable future that could involve significant limitations. As such, these two participants needed to



account for the unique implications of their respective illnesses when considering disclosure to potential partners.

Aurelie also talked about concerns related to disclosing her cancer history to potential partners, in addition to noting that the intensity of her treatment had hindered her from dating previously. Despite not being certain of how she would manage the disclosure of her illness history, Aurelie discussed upcoming plans to meet a young man that she had come in contact with on the Internet:

*I'm just in contact by phone, and I will see him for the first time... I will see him on Monday. So he knows that I wear often a hat, but he doesn't know exactly why, and um, um, I'm a bit afraid of telling him but I want to tell him [face to face], not by phone or email. And, uh, his mother died from cancer so I think he will understand for sure, but I'm not sure that a boy wants to, to date a girl with, or who has, uh, been through cancer.*

This comment captures Aurelie's dilemma regarding the disclosure of her illness: she would like to tell the young man with whom she has talked on the phone and emailed, but she is afraid of his reaction and the possibility of rejection. The need to negotiate the timing of disclosure has been identified as a common issue for young adult cancer survivors, who link the possibility of rejection by potential partners to the physical and psychosocial issues that often persist after treatment is complete (Odo & Potter 2009). Thus, Aurelie's consideration of managing disclosure with a potential partner reflects the experiences of other young adults with cancer, as well as other young women affected by serious illnesses like Leanne and Sandra. This finding provides evidence that illness may play a significant role in dating and negotiating potential partnerships for young women with a variety of illnesses.

As a whole, this sub-theme offers insight into the effects that illness had on relationships with partners or dating for eight of the young women, with two participants not addressing this topic. The five young women who were in long term relationships discussed the support that



their partners offered them, as well as specific issues that had arisen in their relationships due to illness. While partners were important sources of care and support, participants worried about the impact that the ongoing or lasting implications would have on their relationships. Some participants, such as Nicole and Laura, also experienced guilt because of the complexities that illness brought to their relationships. In addition, illness introduced issues related to infertility and having children for Laura, Nancy, and Nicole that were perceived as having potential to jeopardize their relationships. Further, illness and its treatment could be detrimental to intimacy and sexuality, also placing strain on relationships with partners. While Melanie already had two children when diagnosed, she was faced with another new set of issues as she tried to manage her health and support needs alongside those of her husband and children. Finally, illness also raised a number of concerns for Aurelie, Sandra, and Leanne, who had many questions about the appropriate time to disclose their ill status or history of illness to potential partners. Although disclosure when dating has been identified in the existing literature on young adult cancer survivors (Odo & Potter 2009), further examination of this topic could identify ways in which young adults successfully manage this issue.

### *6.3.3 Relationships with Friends*

In addition to talking about the negotiation of relationships with family members and partners, many of the young women discussed the value of friends because of the support that they offered. Some participants indicated a greater appreciation of their friendships as a result of the illness experience. However, some participants also talked about relationships with friends in negative terms, as friendships sometimes became problematic as a result of the illness



experience. Specifically, restrictions brought about by illness or the inability to maintain reciprocity was reportedly detrimental to relationships. Further, participants discussed how some relationships became focused on illness, which was viewed as a negative outcome. However, Nancy offered insight into the balance between obtaining support for illness-related issues and maintaining normalcy in everyday life. Therefore, this sub-theme highlights a number of issues pertinent to how young women's relationships with friends may be affected due to illness.

Primarily, participants spoke of relationships with friends in positive terms. Stacey, Sandra, Aurelie, Leanne, Nancy, Nicole, Melissa, Melanie, and Elizabeth all explicitly mentioned one or more friends who were central in providing emotional, instrumental, and/or informational, support during the illness experience. For example, Stacey described some of the ways that her friends had been supportive, one of which was depicted in the photograph below:

*It's been amazing to have such wonderful friends because I've learned in my adult life that you have a family but then you have a whole other family that you choose, that you invite in. You know, the people that come to visit me when I'm in the hospital and, and will run your errands, and people who brought meals after we got home, and my girlfriends who unpacked the \$5000 worth of stock [for our store shown in the photograph] that arrived while I was at hospital... They were amazing.*





Stacey elucidated the value that she placed on her friends who had supported her through the duration of her illness experience, partly because her relationship with her parents had suffered. Melanie also talked about how her friends had rallied around her when they found out about her diagnosis, some of whom initiated producing a calendar to sell in order to raise money for breast cancer research.

For Elizabeth and Nancy, each had one friendship in particular that proved to be pivotal during the illness experience. As discussed in Chapter Five, a friend of Nancy's had recommended a book that turned out to be a crucial informational source. Elizabeth, on the other hand, focused on the emotional support that she had received from one friend, recalling:

*On the sideline I had one friend who, uh, you know, just, she was there through it. I remember being able to talk to her and that was something very huge... I felt like I could talk to her more honestly than my family... I guess she just took me under her wing and, and I really needed that and appreciated that. Um, just kind of [having] an outlet I guess.*

Here, Elizabeth related the importance of being able to share her feelings and concerns to the coping process, emphasizing that efforts to listen and understand were valuable forms of social support. The desire to talk about illness with friends and receive validation is reported in a case study of a young cancer survivor who agonized over some friends' perceived lack of acknowledgement of what she was going through (Lee 2001). In accordance, Elizabeth was appreciative that she had such an empathetic friend.

Aurelie also talked about the importance of support from friends to the process of coping with cancer. She used the following photograph to broach this subject, explaining:

*So, I couldn't take a picture of my friends because it was too complicated... so I just took a picture of what they sent to me at the hospital just after my surgery... Each person has put a little message or a little picture... I wasn't expecting that and I was so happy, um, because I was just operated [on], and so friends are a good support too... It's quite those little messages that makes you feel, um, stronger to fight the disease... that people think of*



*you... And it makes me think of them and remember all the good moments that we had and that we will have in the future.*



Aurelie noted that such an indication of her friends' care and concern was greatly appreciated and contributed to her resolve to cope with illness. Thus, although many of her friends could not visit her personally, their messages made her think of them and have hope for the future. In addition, efforts made by friends to support Aurelie during this time kept her connected with her life prior to illness, which may be especially important to young adults (Lynam 1995).

Similar to others, Sandra developed a greater appreciation of her friends as a result of her experience of MS. She reported receiving support from friends in a variety of ways, including informational support that was important to making decisions about treatment, as discussed in Chapter Five. As well, Sandra's boss at work was also a good friend who was instrumental in ensuring that she could work from home in the event that she experienced ill health or physical limitations in the future. Sandra expressed her gratitude in respect to the photograph below:



*This is my Christmas card set up, um, you asked about changes and I realized that this year was the first year in a number of years that I managed to get Christmas cards out to people in my life, and that was a really important thing for me to accomplish. I really wanted to do that, um, just because I appreciate having people in my life so much, especially more since this diagnosis, that I really want to recognize them as much as possible, so Christmas is a nice way to do that.*



As Sandra described, she was making an effort to be more proactive in expressing her appreciation of her friends and the support that they had offered her. Leanne shared this sentiment, noting that the illness experience brought about the realization that: *Now I know that [my friends] care about me, I know that they love me for who I am.*

Although relationships with friends usually continued or intensified due to illness, some participants reported negative outcomes for friendships or interactions that were viewed as problematic. For example, Nicole recalled that the restrictions on her social life resulting from illness, which were discussed in more detail in Chapters Four and Five, led to the breakdown of one friendship. She stated:

*We were really good friends, um, and then she just turned 20 now and she's big into the bar and all that and doesn't understand why I don't like go with her. And she's like 'You never want to hang out.' I'm like 'I can do anything but that.' And it's just a different lifestyle so it's, we're not really that good of friends anymore because that's all she wants to do and I don't want to do anything like that.*



As described in this quotation, Nicole had drifted apart from this friend because she did not understand the implications that epilepsy had for her social life.

Melissa also discussed the dissolution of some friendships, particularly of those friendships that were not particularly close prior to her experience of ill health. She said:

*I didn't have the energy to go out and socialize with them. The ones who are really close are the ones who stayed and cared anyways, and the ones who, you know, were maybe not as close as friends, there were a couple of them that really came through for me when the crises happened, but most people just pulled away. And so that was hard because it, you know, that's the time that you want people to be around.*

Melissa indicated that, while some friends were very supportive, others were not. The 'disappearance' of friends because of illness is an issue identified in the existing literature on young adults affected by cancer, in which young adults communicated that some friends were unable to understand the issues raised by having a life-threatening illness (Lynam 1995; Odo & Potter 2009; Rowland 1989, cited in Lee 2001). Leanne also noted that one close friendship dissolved because she was unavailable during her hospitalization to support that friend through the death of her grandfather. Thus, friendships may also be affected because illness can limit affected individuals' ability to fulfill expectations of reciprocity.

Some participants also talked about how illness had now become the focus of conversations with friends and other acquaintances, which was a source of frustration. Nicole talked about this problem when returning to her former place of employment to visit friends who still worked there. As well, she recalled how her Medic-Alert bracelet draws attention in interactions with others. In relation to the following photograph, Nicole said: *I don't ever take [the bracelet] off so I get used to wearing it, but some people are like 'Oh, what's that?' and they'll ask and it's fine but sometimes it's just a bit upsetting and I just want to take it off. I don't want to wear it, like I don't want to have to have a symbol that I'm sick.*





Thus, Nicole resented that her Medic-Alert bracelet drew such attention from others and divulged that she had a serious illness, particularly because she perceived epilepsy to be poorly understood and stigmatized, similar to what is reported in other research (Ablon 2002).

Melissa shared similar frustrations to Nicole, indicating that she withdrew from others somewhat because she resented that she was constantly being asked about her health. Thus, both Nicole and Melissa disliked feeling as if they were being treated differently, wanting instead to carry on with 'normal' life. Young adult's desire to maintain or return to a sense of normalcy in their lives is evident in the literature on young adults with serious illness (Kyngas et al 2001; Miedema et al 2007), and will be further discussed in the final chapter. However, it is worth noting that some literature suggests that ill young adults often want to communicate about illness but find that their friends wish to avoid such a topic, rather than vice versa (Lee 2001; Lynam 1995; Stewart 2003, cited in Hilton et al. 2009), which is contradictory to the comments shared by Nicole and Melissa. Although these participants were open about their ill statuses, some young adults may choose to withhold information about their ill status from friends and colleagues in order to avoid changes in relationships or being treated differently, as is the case



for some young adults with serious illnesses (Hilton et al.; McCann & Clark 2004; Raty et al. 2007).

Nancy offered some particularly insightful comments regarding communication with friends about illness and the visibility of illness. In respect to talking about illness with friends, Nancy related:

*The conversation's kind of like weird 'cause it's just like I don't really know what's going on. It's not really something...it's kind of like it's my own thing, you know? 'Cause like people can't see anything, right, 'cause I just look like a normal person - whatever that means... Whereas like with an illness that actually has like outside appearances, like people would be, um, more apt to assume that there is something to talk about there. Whereas, yeah, there is something to talk about but, 'Okay, it's not working and I don't know what to do.' Like where do you go from there? You know, or people might be more inclined to ask questions if there was like a physical thing... I think a lot of my friends just like forget that I have [endometriosis], which is good because then it's not like I'm treated like this weird diseased person. But then at the same time it's just like, it's kind of hard to bring it up. It's like this forgotten subject.*

Here, Nancy called attention to the idea that it was difficult to communicate with friends about illness because the lack of visible signs of illness, in addition to her uncertainty of what was going on, made it harder to broach in conversation. However, Nancy also suggested that the invisible symptoms of endometriosis meant that her ill health did not change the way that her friends treated her. Thus, she perceived the invisibility of her ill status positively and negatively, but recognized that more visible symptoms may yield greater attention from others and thus more support. Sandra shared similar comments regarding the benefits of having an 'invisible' illness, noting that she was selective in who she disclosed her ill status to.

Participants' comments on relationships with friends reveal the need to negotiate a variety of issues. While all but one participant discussed the importance of support from friends during the illness experience, some of the young women also noted that illness had negative



repercussions for some relationships. Particularly, some friendships dissolved as a result of restrictions resulting from illness or because illness inhibited reciprocity in the relationship. Relationships were also described in negative terms when illness became the focus of the relationship, as this disrupted the former basis of the relationship and made some young women feel as if they were being treated differently. However, one participant recognized that negotiating support with friends was difficult; specifically, if the illness was not visible to others, the affected individual would not be treated differently, but this could make it difficult to broach the topic and solicit support. As a whole, this theme highlights the importance of support from friends, and the need for some participants to negotiate complex relationships with friends because of the implications of illness.

#### *6.3.4 Seeking Support from Similar Others*

In addition to family, partners, and friends, some of the young women discussed the importance of encounters with similar others. Similar others were typically other individuals facing the same illness, some of whom were young adults and some of whom were individuals of different ages. Participants typically came in contact with similar others through support organizations or while acquiring health care services. While similar others were viewed as crucial sources of support by most participants, some reported that they lacked similar others with whom they could communicate with and relate to, which contributed to isolation during an experience that was already disruptive to their young adult lives.

Examples of the benefit of similar others were given by Stacey and Laura, who talked about meeting other young women affected by breast cancer through support services and at conferences dedicated to this population. Through her involvement as a peer supporter, Stacey



had come into contact with several other young women affected by cancer whom she described by saying: *Every one of the people I've been matched with, I've ended up really hitting it off with, um, and so I sort of have that informal network of people that you can kind of kibitz with about the things that frustrate you with the system or any of those kind of things.* Stacey emphasized that this group of similar others were valuable sources of support because they could relate to her experiences. As such, Stacey believed that she has a number of people to whom she can turn if she has questions or needs advice about breast cancer and its treatment. Further, both Stacey and Laura had attended conferences for young women with cancer where they had engaged with others who faced many of the same issues that they did. Laura communicated the significance of attending such a conference by stating: *It's nice just having people around you that are like you or that, you know, you can really identify with and who understand.* In saying this, Laura communicated the comfort that she gained from knowing that there were other young women similar to her who could relate to what it was like to have breast cancer at a young age. Laura's comments echo those of a young man cited in a study of young adults with cancer who stated that he took comfort in knowing that there are others who were "*in the same boat*" (Hoody, quoted in Grinyer 2007, p.47).

While Laura and Stacey felt a greater connection with young women affected by breast cancer, Aurelie and Elizabeth found other individuals affected by their respective illnesses to be supportive, even though few or none of them were similarly positioned in the life course. Aurelie reported that she had found valuable support from other individuals with cancer, including those she met while in treatment and the members of a brain tumour support group. In relation to the support group, she said:



*So I started to go the month after I was diagnosed and, but it's mostly people older than me, I am the baby. And it's like a family now because we just discuss and, as there are always the same people, we started to know each other very well, so it's like a family... So yeah, and it was good to know because they speak about chemo and they speak about radiation. It can be different but it's good to know what possibilities we have and what was used to treat them or their friends.*

Although the support group is comprised of individuals of many ages with various types of brain tumours, Aurelie described the members as being like family to her because of their support and caring. Their support was especially important for Aurelie as she lives far away from her family. As well, she felt that the group members were a valuable source of information regarding treatment, as health care providers could not really tell her what it was like to have chemotherapy or radiation therapy.

Elizabeth also described seeking out a support group to attend, which was composed of individuals several years older than her who also experienced depression. Although she did not share the specific situations as the other members, she appreciated the empathy offered and respectful atmosphere in which she felt that she could openly express herself without judgement. Rich (2006) proposes that bonds with similar others are important, particularly for individuals with stigmatized health problems such as eating disorders (although the type of support offered by similar others can vary and may not be beneficial to recovery in such cases). Thus, Elizabeth and Aurelie's discussions of the support gained from similar others suggest that the shared experience of illness and ability to be supportive may be of greater importance than shared life stage; however, when the number of individuals affected by an illness is high, young adults may seek out others with similar backgrounds to themselves as Laura and Stacey did. Above all, the four participants who sought the support of similar others emphasized that individuals with similar experiences of illness were significant sources of information and support and aided in the coping process.



On the other hand, some participants discussed a disinterest in support groups for a variety of reasons, one of which was the perceived lack of similar others. For example, Nicole said: *If I went to a support group, like would it be people my age or would it be parents of kids? You know? It would be kind of hard to talk to them 'cause my situation's really different.* Here, Nicole suggested that she would likely feel out of place at an epilepsy support group because she perceived this illness to be commonly diagnosed among younger individuals. Thus, the uniqueness of her situation led her to believe that similar others do not exist. Sandra also believed that support groups for MS would not include others like herself, as she thought that individuals who attend such support groups were those for whom the illness had progressed. However, Sandra expressed a desire to find similar others with whom she could relate, saying: *I really would love to meet someone who's exactly like me, you know, my age, my health level, um, my life, you know, no kids, not married, whatever, having a good time, but has MS.* Nancy also reported a lack of similar others with whom to share experiences, noting that she had not encountered a support group or any other support services for women with endometriosis. Thus, her mother and aunt were the only other women that she knew who had experienced endometriosis.

Participants' comments emphasize the perceived importance of similar others to the coping process, in that their shared experiences create a common ground for relating to one another and offering information or strategies for coping. While Laura and Stacey indicated that other young women with breast cancer were crucial sources of support, Aurelie and Elizabeth had found that individuals of all ages affected by the same illness were supportive, despite variations in experience. The importance of similar others to the coping process has not been thoroughly examined in existing research on young adults with serious illnesses, although some



research has considered this topic. Grinyer (2007) reports that young cancer patients often experience reduced feelings of isolation as a result of the peer support and knowledge gained from other young people with cancer staying in the same hospital ward. In particular, young people with cancer may benefit from knowing that others like themselves exist. However, Grinyer also indicates that some young people may not form friendships with other young cancer patients, and those who do may experience the death of such friends as particularly traumatic. Nonetheless, Grinyer argues that the potential for supportive relationships and decreased isolation confirm the value of having a specialized health care services for young people with cancer, which may also be beneficial to young people with other types of illness.

Despite that Aurelie and Elizabeth found support from individuals of a variety of ages, other participants expressed a preference for meeting others affected by their respective illnesses that had similar life situations. The lack of similar others described by some participants compounded feelings of isolation during an experience that was already disruptive to their young adult identities. Specifically, believing that there was no one else in their situation resulted in feeling different and alone, which was problematic for the coping process. However, Sandra's comments also suggest that contact with other individuals whose illness has progressed may also introduce further anxieties about illness, similar to what has been identified in relation to young people with cancer (Grinyer 2007). Therefore, participants' comments offer evidence that contact with similar others can have both positive and negative implications for young adults affected by illness, while the absence of similar others can contribute to further isolation.



### 6.3.5 *Summary*

In this theme, I examined the young women's negotiation of relationships with and support from family members, partners, friends, and similar others. For most participants, family members were the major source of social support, offering instrumental, emotional, informational and/or financial support for which great appreciation was shown. However, some participants also recognized the need to support their family members as they too were affected by the illness experience. Thus, the young women were faced with balancing the concerns of their loved ones alongside their own, and some young women experienced guilt due to the worry and additional burden that they caused family members. Accordingly, the illness experience introduced a variety of practical and complex issues into family relationships that had both positive and negative outcomes. For example, the possibility of a young woman dying from illness resulted in both increased closeness in relationships and difficulty in coping for parents. Other implications, such as limitations in carrying out everyday activities, sometimes were detrimental to relationships with parents and siblings, and contributed to strained communication and a lack of understanding. In the event that relationships with certain family members were unsupportive, the young women turned to other family members, partners, friends, and/or similar others.

Participants who had long term partners reported that they greatly contributed to the coping process through the care and support that they offered. Despite reporting overwhelmingly supportive interactions, these participants also faced a number of issues related to their relationships with partners that included: feelings of guilt, the possibility of infertility, and changes in intimacy and sexuality. Further, illness introduced unexpected issues into intimate relationships that led to conversations that would not have occurred otherwise until much later in



the relationship, such as decisions about having children. One participant already had children and thus was required to negotiate their care with her husband along with her own care and support needs. On the other hand, three participants discussed the perceived impact of their ill status or history of illness on dating and the establishment of a partnership. These participants specifically focused on the issue of disclosure and how they would negotiate this with potential partners. Thus, illness had implications for both relationships with partners and dating that added to the array of other issues that participants faced because of illness.

Illness also had implications for relationships with friends. Participants typically talked about their appreciation of friends, even if their friends did not fully understand what they were going through. On the other hand, some friendships suffered as a result of the illness experience because of restrictions brought about by illness. For example, illness sometimes changed participants' social life or limited the reciprocity in the relationship, contributing to the dissolution of friendships. Difficulty with friends due to a lack of communication or understanding is reportedly an issue experienced by young adults with cancer (Lynam 1995; Odo & Potter 2009; Rowland 1989, cited in Lee 2001). However, illness also brought about relationship changes and frustrations for some participants when it became the primary focus of the relationship. As such, some participants chose to pull back from certain relationships themselves or did not disclose their ill status or illness history in order to avoid being treated differently. Other participants indicated that the 'invisibility' of the symptoms of illness created a situation in which their ill status could go unnoticed and therefore un-stigmatized, but also potentially unsupported. Thus, similar to their relationships with family and partners, participants had both positive and negative experiences with friends.



Finally, participants considered the support that they had received from similar others, who were individuals affected by the same illness. Two participants expressed the importance of sharing experiences and information with similar others who were also young adults, whereas two other participants reported the value of support from similar others of a variety of ages. While a variety of reasons contribute to why this may be, it is more significant to recognize the emphasis placed on shared experiences by these participants. Knowing that someone else had experienced or was experiencing the same situation offered comfort and aided in coping. On the other hand, participants who had not found similar others with whom to share their concerns communicated feelings of difference and isolation. Thus, participants' comments suggest that similar others were perceived as beneficial in providing support and information. However, it was also recognized that similar others whose illness had progressed could be detrimental to the coping process. As such, young adults affected by serious illness may have specific preferences regarding similar others as a potential source of support; however, the availability of similar others with shared characteristics (e.g., time since diagnosis, age, gender, stage of illness) may be beneficial even when such individuals are not utilized as sources of support, because awareness of similar others could lessen feelings of difference.

As a whole, this theme highlights how participants managed the implications of illness for their relationships and negotiated social support with family members, partners, friends, and similar others. It repeatedly came up in the interviews that members of each of these groups were important sources of care and support upon diagnosis of illness and throughout the illness experience. However, some participants reported negative outcomes for relationships as well. Perhaps most surprisingly, some parents were viewed as unsupportive, which may be attributable to their difficulty in coping with their child being ill. In addition, some friendships dissolved due



to a lack of understanding of illness and its implications. While relationships with partners were viewed positively, the five young women in long term relationships faced issues that could potentially be problematic for their partnership. Thus, the illness experience posed practical and complex issues for relationships with family, friends, and partners. Finally, despite the importance placed on support from loved ones, participants valued the social support received from similar others who could relate to what they were going through, and struggled when similar others were not available.

In highlighting issues related to relationships and social support, I demonstrate the pervasiveness of illness, as well as the complexity of negotiating illness in social interactions. Specifically, illness had significant implications for participants' relationships and required the negotiation of social support, in addition to affecting various other aspects of their lives. In the following chapter, I discuss one final theme that ties together the themes examined in this chapter and Chapter Five, and offer implications and conclusions drawn from my analysis of the research data.



## **Chapter Seven – Making Sense of Illness:**

### **Discussion, Implications of, & Reflections on the Research**

*[Illness is] just another challenge that you have to deal with. It's just something that I have to learn to adjust [to].* (Nicole, epilepsy)

#### **7.1 Introduction**

In this last chapter, I explore one final theme emerging from the young women's stories of illness, which was related to making sense of illness. This theme calls attention to participants' efforts to understand and find meaning in their experiences of illness, a process that is intertwined with each of the themes that I have discussed previously in Chapters Five and Six. This section is followed by a discussion of the research findings as a whole that highlights what can be gleaned from them. In addition, I suggest some implications of the findings for health care and support services. These two sections therefore outline what has been learned through the study of these young women's experiences of serious illness and how this knowledge can be applied. I next offer some reflections on the study itself and the benefits and limitations of the methodological approach and methods with which I engaged. I conclude the chapter with a review of the argument put forth in the dissertation.

#### **7.2 Making Sense of Illness**

Participants sought to make sense of their experiences of illness in various ways. According to Langellier (2001), attempts to make sense of illness can restore individuals' sense of agency in the experience (cited in Manderson et al. 2005, p. 326). As such, participants



entered into the complex process of trying to figure out why illness occurred and how to proceed with life in light of illness. This process involved participants' drawing on dominant discourses and cultural resources related to health and illness, particularly from biomedicine and the media (Lupton 2003). Thus, I demonstrate how many of the young women sought to make sense of illness through: considering possible aetiologies, searching for meaning in the illness experience, and wanting to move on with life. This closing thematic section provides evidence of the young women's efforts to reconcile the multitude of physical and psychosocial disruptions brought about by illness with their self identity.

#### *7.2.1 Considering Possible Aetiologies*

One aspect of making sense of illness involved reflecting on possible factors that contributed to the onset of illness, such as: genetics, lifestyle characteristics, previous medical procedures, or aspects of their social environment. Although participants were not able to verify the actual aetiology of illness, identifying a likely cause was important to the sense-making process for several participants. Most often, participants offered biomedical explanations for illness that they had been offered by health care providers or had discovered when researching illness. Such explanations attributed the presence of a serious illness during young adulthood to genetics or an abnormality that had been present since birth, as was evident in the stories of Aurelie, Sandra, Nicole, and Nancy. Considering such a possibility allowed these participants to view it as inevitable or unavoidable. The attribution of illness to genetics by several participants also validated the idea that illness was out of their control and thus absolved personal responsibility for illness, as proposed by Lupton (2003).



For example, Aurelie discussed the cause of the tumour found on her brain by saying: *It's genetics. I am scientific and I know how genetics work and, so yeah, I've got one chance out of a million, but [the tumour] fell upon me and I have to live with that. Small children with leukemia have to deal with that and, uh, they did nothing.* This comment highlights Aurelie's belief that the existence of a brain tumour was linked to genetics and that she was not responsible for it because of its presence since birth, an explanation that fit well with Aurelie's background in science and her rational approach to problems. However, this comment raises a question as to why biomedical explanations of illness are preferred; specifically, despite the reputations of these expert discourses as being founded on rational principles (Lupton 2003), the causation of illness remains contingent and uncontrollable, as evidenced in Aurelie's comment that she had *one chance in a million*. Therefore, such explanations do not necessarily offer definitive meaning because a specific reason for illness remains undetermined (i.e., why one individual is inflicted with illness and another is not). However, I believe that genetic explanations of illness are preferred because they offer comfort to individuals affected by illness through the absolution of personal responsibility for illness, in that there is perceivably no way to avoid a genetic illness. In other words, these explanations enable individuals to feel as if illness was out of their control, while also believing that there is a rational explanation for the occurrence of illness.

Laura and Melanie also reflected on the possibility that genetics were responsible for their occurrences of breast cancer. Laura indicated that she had looked into genetic testing because her young age at diagnosis and father's history of prostate cancer made a genetic component likely. Melanie shared a similar experience, saying:

*I filled out [paperwork for genetic testing] because my dad's whole entire side have all passed away from cancer... I know that, um, his mother had breast cancer, he had cancer, and my grandfather did. But everybody keeps telling me that you don't get it from*



*your father's side, but from going back and looking at genetic stuff, you get one from your father and one from your mother, so it's obviously gotta come from somewhere.... It's not like I ate it, you know?*

Here, Melanie described how the history of cancer in her father's family generated suspicions that she had a genetic predisposition for cancer. Additionally, her concluding comment makes reference to her belief that lifestyle characteristics, specifically diet, were not a factor in the development of cancer, thus absolving herself of responsibility for the illness.

Participants' preferences for genetic or biomedical explanations of serious illness reflect existing research on women affected by depression who experienced their diagnosis as validation of a legitimate illness rather than a personal flaw, and evidence that illness was unavoidable (Lafrance 2007). Thus, biomedical explanations enable the maintenance of individuals' moral character in a socio-cultural context where individuals are portrayed as personally responsible for their health (Gustafson 2005). Given the multitude of possible factors contributing to cancer, the attribution of cancer to genetics may be beneficial to coping for many individuals, despite working against health promotion efforts that depict the prevention of cancer as a personal responsibility. However, the ability of individuals to avoid carcinogens is not necessarily a personal choice (with the exception of certain behaviours such as smoking) because of environmental exposure, therefore suggesting that individual blame for illness is not warranted and may be detrimental to coping.

Despite the reliance on genetic explanations of illness by several participants, some participants considered alternative aetiologies. For example, Nicole, Nancy and Melanie talked about the possibility that illness resulted from a prior medical procedure or medication. In addition, several participants talked about the role of lifestyle characteristics and social environment in the causation of illness. Although Laura recognized the likelihood of a genetic



component, she pondered the role of her lifestyle choices, stating that she experienced a *huge guilt trip* following her diagnosis. She continued on to say: *It's like 'Oh my God, that time that I ate...' You know?* Thus, Laura expressed feelings of responsibility for having breast cancer, despite also recognizing that she leads a comparatively healthy lifestyle. Laura's comments reflect Lupton's (2003) observation that the blame typically placed on ill individuals leads them to defend their past behaviour to others or to accept responsibility that they did not do enough to prevent illness, despite that causal factors are far from being fully identified and described by the scientific community.

In addition to diet and other lifestyle behaviours, the role of stress in the illness experience was also considered by some participants. Stacey, in particular, talked at length about how she viewed cancer as being related to her stressful lifestyle. She described her former need to fill her schedule with as many obligations as she could, and her belief that her three cancer occurrences were warning signs that she should reduce the amount of stress in her life. Stacey's comments speak to those reported in a study of women affected by gynaecologic cancers, many of whom viewed stress as contributing to physical vulnerability and increased susceptibility for cancer (Manderson et al. 2005). As well, her comments about stress reflect the findings of a study of women with depression, in which some participants described perfectionist tendencies as contributing to physical and emotional exhaustion that resulted in depression (Lafrance & Stoppard 2006). Other participants also discussed the possible contributions of stress to the causation of illness, including Sandra and her mother, and Elizabeth. Consideration of the role of stress in the aetiology of illness by these participants highlights the widespread view in industrialized countries that individuals are responsible for their health and can control illness through preventive measures and healthy behaviours (Ibid), even though stress itself is a



complex and multi-faceted concept. Therefore, ill individuals are blamed for not managing stress appropriately and thus inviting illness (although Manderson et al. point out that such a view does not account for the multiple levels at which stress is encountered, making stress potentially unavoidable for individuals because of modern life, marginalization, and/or poor material and emotional circumstances).

As the above paragraphs demonstrate, participants' discussions of illness aetiology centred largely on their struggle with the possibility that they were somehow responsible for illness. As previously discussed in Chapter Five, Nicole and Laura specifically noted that they found it difficult to accept their diagnoses knowing that they had not done anything to cause their illness. However, Laura also considered the lifestyle choices that she made in order to defend herself against blame. While some participants talked more subtly about responsibility for illness, almost every one of the young women at some time considered the role that they may have played in illness causation. As such, reflections on the role of exercise, diet, and stress emerged amidst participants' considerations of biomedical explanations. Despite feelings of responsibility, many participants preferred to believe that illness resulted from genetics or abnormalities present since birth because such explanations diminished feelings of blame for their illness to some extent. However, there is an interesting tension between participants' considerations of possible aetiologies: while genetic explanations allow for the possibility that illness was outside their control, behavioural or environmental explanations offer a more definitive cause that could be controlled in the future, such as the adoption of certain lifestyle behaviours. Thus, identifying a causal factor that can be controlled may help to restore a sense of agency to the illness experience.



Participants' reflections on aetiologies and the existing literature cited in the above paragraphs highlight how considerations of possible aetiologies of illness are an important part of making sense of illness. Specifically, participants wanted to identify potential causes in order to determine why illness had occurred, which assisted with the coping process. The identification of a cause outside of their control was helpful for some participants to resolve feelings of blame associated with illness. On the other hand, the identification of something potentially within their control, such as stress, was helpful for a few participants in that it seemed to offer a concrete way to deal with illness and possibly prevent it in the future. Thus, participants considered two types of possible aetiologies that were helpful to coping, as well as making sense of why illness had happened.

#### *7.2.2 Searching for Meaning in the Illness Experience*

In addition to trying to understand the onset of illness, participants sought to make sense of it by looking for meaning in their experiences. However, some participants indicated that finding meaning was difficult or an ongoing process. Leanne highlighted the complexity of trying to understand her experience of anorexia, saying:

*I don't know how to make sense of what happened. I just think it had to have happened for a reason, but I don't know what that reason is and I don't know how to explain it any better than that... I can't say 'This is why.' I mean, there [are] factors that contributed to it, but you can't say you have an eating disorder because of that. It's a whole bunch of things... But why did this whole thing have to happen in the first place? You know, why did I have to be who I was? You know, it has to be for a reason. It has to be something.*

Here, Leanne recognized that a number of factors contributed to the onset of anorexia, but that these factors do not offer her with an overarching way of finding meaning in her experiences. As such, Leanne's comments demonstrate the complexity of trying to find meaning in illness, a sentiment that other participants shared, including Sandra and Laura. Thus, these participants'



comments reference the “quest narrative” that is commonly adopted by ill individuals, in which illness is viewed as a journey from which new insight into life is gained or transformation is brought about (Frank 1995). However, these participants indicated that they had not gained such insight from the illness experience, and believed that finding meaning in illness was a process that involved time to adapt and reflect.

However, several participants also talked about different realizations that had come about because of illness, which endowed the illness experience with meaning. For example, some participants revealed that being ill had led them to learn new things about themselves or their lives. Stacey proposed that coming to terms and making sense of illness was a process that she was engaged in on a daily basis despite being several years past her initial diagnosis. Although she was involved in the ongoing negotiation of the implications of illness, Stacey viewed illness as a warning sign that her life was not in balance, which she explained in relation to this photograph of her yard on her wedding day:



*There's this calm quality about that river [in the background] that kinda runs past our front yard, um, just to kinda show that, you know, we chose this to kind of try to get a little bit better handle on the emotional chaos that was going on in our lives, and to, to get back to a sort of simpler way of life. Every once in a while I get way off over here [gestures away from herself] again and I need to remind myself to, you know, take better*



*care [of myself]. When we're there and we don't leave the yard, there's this calming thing that, you know, that has kinda given us that 'Aha, we need to, you know, take better care of ourselves emotionally and rest and enjoy and press pause.' And that's what living where we live does.*

Melanie also described her breast cancer diagnosis as *a wake-up call* to make changes in her life and value her time with family to a greater extent, while Laura and Leanne shared similar thoughts regarding the realization made as a result of illness that they needed to obtain greater balance in life. Specifically, illness was a catalyst for each of these young women to spend more time doing what they enjoy and less time working or doing things that caused them stress.

In addition to making lifestyle changes and seeking greater balance in life, finding meaning in illness also involved participants making realizations about what is important in their lives. As mentioned in Chapter Four, Aurelie talked about a shift in her priorities that had occurred, saying: *I don't really care about work, like we need money to live but... Being happy and making others happy [is what's important], and trying to speak about my experience and help others more... I don't say 'I want a new cell phone.' No, it's more important than that.* In addition to offering new insight into what is important in her life, Aurelie also indicated that she ensures that she spends time relaxing and being with friends more so than in the past. She talked more about this realization, using the photograph below as an illustration:





*I took this picture... to say that [individuals affected by brain tumours] don't care about futilities anymore and we enjoy life... We don't get really angry anymore, as we did before. And the cats are here to represent that... We enjoy having them ...even if, um, they are sometimes quite annoying or quite boring, or they put dried food everywhere in the house, or if they wake up you at 4 in the morning, uh, scratching at your door... Just to forget futilities and just focus on [good] things in life.*

This quotation and photograph highlight the meaning that Aurelie discovered in the illness experience; specifically, a greater awareness of the fragility of life has led her to have a new outlook in which she does not worry about minor problems and inconveniences, such as the cat waking her up in the middle of the night. Laura made a similar comment, stating that she now focuses on *not getting as worked up about stuff that doesn't matter*.

Some participants also described changes in their sense of self that had resulted from illness. Particularly, having coped with a serious illness brought about recognition of their inner strength and confidence. Both Stacey and Melanie talked about such realizations about themselves in relation to having breast cancer. For example, Stacey stated:

*I've gained some confidence in myself that I guess maybe I would have gained anyway as I grew up through my 30s but, um, I felt like it gave me some substance because before... I don't know if people took me seriously. But having had the cancer and being comfortable talking about it felt like it gave me some depth of character that I probably wouldn't have earned until into my 40s if I hadn't gone through this... I enjoyed that I had this thing that I had come through that gave, that made people understand that I wasn't a powder puff, you know?*

Here, Stacey highlighted her view that illness had contributed substance to her character and increased her confidence, particularly in relation to her employment. Melanie also shared a similar belief, saying:

*To me, if I fail, Oh well, then I'll try something else, you know, I'll try it a different way. Where before if I failed, it was 'Oh my gosh. I failed.' But now it doesn't matter because you learn from mistakes and you learn from other things and you know, if you do make a mistake, it's okay, you know, life goes on.*



Melanie's comment speaks to the shift in her approach to life since being diagnosed with breast cancer: having a life-threatening illness has given her reason to worry less about failing and more about making the most of the time that she has. As such, both of these participants indicated that the illness experience led them to be more self assured and confident in their abilities.

The above quotations from Stacey and Melanie demonstrate how they constructed a positive identity based on their ability to cope with breast cancer. Such portrayal of oneself in the interview context is similar to that of women in a study of chronic pain who emphasized their strength while downplaying that of other women (Werner et al. 2004). The authors of this study propose that constructing such a positive self-image is a moral act in which participants struggled against stereotypes of ill women as "crazy, lazy, illness-fixed or weak" (p.1043). Similar resistance is observed in a study of adolescent females with anorexia in which participants sought to construct a positive identity based on the strength and empowerment yielded from the anorexic experience (Rich 2006). Thus, in this sense, illness was portrayed positively by these participants as contributing to the substance of their character, rather than as a negative or stigmatizing experience. However, the construction of a positive identity in this sense does not suggest that these participants necessarily viewed cancer as a positive experience on the whole, as they also experienced immense disruptions to their everyday lives and plans for the future.

While participants frequently discussed how the illness experience generated new-found realizations about the self, they also indicated that it contributed to their ability to be empathetic toward others. For example, Nicole suggested that she better understood what it was like for others to live with an illness or disability, while Stacey reported that she has become more compassionate to others during times of hardship or loss. Leanne also believed that her experience of illness would be beneficial to her in terms of her career aspirations, saying that:



*[Having experienced an illness] makes me better equipped to counsel. Because not everybody's going to have gone through, obviously, an eating disorder, but I understand what it's like to go through a major life event, and... I've come back from it. So I know that change is possible.*

Thus, Leanne believed that the illness experience endowed her with the ability to better understand others going through difficult life events and strategies for coping.

Elizabeth also talked about how her experience of depression was meaningful in the sense that it illuminated new possibilities for her future. She took several versions of the image below as an artistic representation of her experiences, highlighting the isolation that she felt during that time (represented by the figure on the right) and how hope has come to overshadow



depression. Elizabeth talked about this shift by saying: *Now, I don't know exactly where I'm going but, um, there's more like aspiration and, you know, more like, some excitement and basically during that time... there's wasn't much hope or anything else. So, um, I think now where I see myself contributing would be different from prior.* Here, Elizabeth reflected on the hope for the future that emerged out of her experiences, and suggested that she might pursue a career related to alternative therapies for ill individuals. Thus, Elizabeth's illness experience contributed to realizations that helped her to find a new sense of meaning in her life. Other participants shared similar experiences or had their past intentions affirmed by the illness



experience. This occurrence was most evident in the desire of several of the young women, including Melanie, Leanne, Laura, Stacey, and Aurelie, to help other individuals affected by illness. Thus, wanting to support similar others was one way that these young women found meaning in their experiences and managed existential uncertainty, as has also been reported by Little et al. (2002).

The above discussion demonstrates the complexity of participants' search for meaning in the illness experience. While several participants related that they had not been able to make sense of their experiences, the young women's comments offer insight into the sense-making process and highlight certain partial meanings that arose because of illness. According to Charmaz (1991), "meanings of illness and self shift and change as illness progresses or recedes into the past" (p.4); thus, meaning is dynamic and related to time and context, as evidenced by the uncertainty, multiple explanations, and contradictions found in participants' reflections on illness. However, many of the young women communicated that they found some sort of meaning in the illness experience and described its impact on their personal and interpersonal well being. These participants' experiences reflect Kleinman's (1988) concept of the "inner moral meaning of chronic illness", specifically that moral lessons can arise from the challenges and pain brought about by illness, which in turn lead to the reconsideration of individuals' lives and social worlds. Examining the process of finding meaning in illness experiences therefore delineates how participants made sense of what they went and were going through.

### *7.2.3 Wanting to Move on With Life*

Despite living with the ongoing implications of illness, the participants all expressed a sense of hope for their future and a need to continue on with life. Moving on with life involved



putting illness in perspective, which I characterize as the “relativization of illness.” This process involved participants downplaying their experiences in comparison to other individuals or other types of illnesses, which helped them to be hopeful for the future. For example, Sandra and her mother discussed how they experienced some relief after medical tests found that she did not have a brain tumour. Laura expressed a similar sentiment in regards to her attendance at a conference for young women with cancer, saying: *A small part of me was grateful that I wasn’t among the metastatic group.* By communicating such feelings, these two participants revealed that their illness experience was put into perspective through the realization that they could have been diagnosed with an illness that was more advanced or life-threatening.

Nicole also described relativizing illness in her reflections comparing epilepsy to other illnesses. In reference to the photograph below, she said: *When I’m, like, upset about [having epilepsy], I’ll just kind of go out and go for a walk with my dog or something and it puts everything in perspective and I’m like ‘I could be so much worse off.’* Nicole continued:



*I’m at the lower end of the spectrum, like I didn’t get diagnosed with cancer or anything else like that. So for me it was a lot easier to say ‘This is something I have to deal with*



*and it's not the end of the world, it's not the end of my life, I have to move on... It's not a death sentence. It's something that, it's just another challenge that you have to deal with.' ...It's just something that I have to learn to adjust [to].*

Here, Nicole referenced a perceived spectrum or hierarchy of illnesses in which some are deemed to be more serious or limiting than others.<sup>7</sup> As such, Nicole believed that epilepsy, in comparison to other illnesses, had less severe implications for her life, which helped her to cope with the limitations it introduced in her life.

Stacey shared the experience of relativizing illness, stating that she did not perceive the limitations resulting from breast cancer as detrimental to her well being in comparison to those experienced by chronically ill individuals who must negotiate aspects of illness on a daily basis. Comparison to other individuals with brain tumours also offered Aurelie perspective on her experience by reminding her of all the things that she had already experienced in her life, unlike younger individuals. Several studies have reported that downward social comparisons are often employed as a coping strategy by ill individuals to protect their psychological well-being (see studies cited in Bogart & Helgeson 2000, p.549; Finlay, Dinos & Lyons 2001, p.580); specifically, individuals may compare themselves with others deemed to be “worse off” in order to cope with the implications of illness, as was the case in a study of women with ovarian cancer (Bowes, Tamlyn & Butler 2002, p.143). However, downward social comparison may also reflect general tendencies for optimism or positive self-presentation rather than a deliberate coping strategy (Finlay et al.). In either case, several participants in this study acknowledged the challenges that other individuals face and their own good fortune in being able to continue with or return to many of their past roles and responsibilities.

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<sup>7</sup> The idea that there is a hierarchical order of illnesses was also discussed by Nancy in respect to the differential application of stigma to certain illnesses and those affected by them. Further, Nancy felt that this hierarchy affected the distribution of resources for research on illness and health care providers' attitudes towards their patients.



In many cases, participants talked about feeling like their life had been on *pause* or that they had *missed out* on a period of time because of their illness. Feeling this way resulted in a desire to move on and to seek a sense of normalcy in their lives. “Normalcy”, according to Miedema et al. (2007), is the predominant goal for young adults who have been diagnosed with cancer, although normalcy does not necessarily refer to the past version of normal life (see also Grinyer (2007) on normality and young people with cancer). Specifically, participants sought to move on through the resumption of past social roles or the achievement of their aspirations. For Melanie, it was both a desire to move on with “normal” life and a necessity because of her family, which she described in relation to this photograph:



*As soon as we found out what it was, I said ‘Get it out, get it done. I can’t wait around for it, I’ve got life to get on with’. Which is probably pretty bad to say, but I wasn’t gonna sit there and dwell on the fact and ‘Oh, woe is me, poor me’ and all this other kinda stuff, you know? You need to get on with life. Too much stuff is happening, let’s just get it done and go from there. Like, mind you, I did have my bawling, freaking out, crying days, but then you pick up and you go on because it’s not just about me, it’s about my kids, it’s about my husband, it’s about our lives, not just my life and feeling sorry for myself.*

Thus, despite being upset, Melanie was driven to carry on with life because of her family roles. Her comments reflect existing research on mothers with breast cancer, who reportedly struggle



for survival and to maintain the motherhood role because of concern for their children (Elmberger, Bolund, Magnusson, Lutzen, & Andershed 2008). Furthermore, such comments highlight Melanie's efforts to construct herself as a good mother and wife through the emphasis placed on her devotion to her family, the implications of which will be addressed in my final discussion of the research findings.

Nicole was another participant who sought to continue with her former roles, despite her initial perception that epilepsy would limit her abilities. She recalled: *My version of epileptics [was that] they seized all the time and they were on medication and their life was pretty much over... So then I was just really upset when it did turn out that's what I had 'cause I didn't want to be like that.* However, since receiving her diagnosis, Nicole's epilepsy was being managed through medication, allowing her to continue on with past roles. She reported: *As far as work, it hasn't limited me, like I'm working two jobs and still going to school so it hasn't limited me in that. I still do everything I did before, it's just I've got to be a little more careful.* Thus, Nicole had re-gained a sense of normalcy in her life through the continuation of employment and education, despite having to take medication and accommodate restrictions introduced by illness. Nicole's experience is similar to those of many young adults with epilepsy and cystic fibrosis discussed in existing research, for whom it was found that 'normal' life included social roles typical of young adulthood as well as ongoing treatment for illness (Badlan 2006; Raty et al. 2007). Other participants also described a return to normalcy through the resumption of past roles and responsibilities, including: Laura who returned to work after breast cancer treatment, Leanne who carried on with graduate school following recovery from anorexia, and Elizabeth and Melissa who continued with their university education in spite of the disruptions brought about by illness.



While many participants continued on with former roles and responsibilities, some also felt a greater urgency to achieve their aspirations or to seize new opportunities. In addition to continuing with work, Sandra spoke about her motivation to finish the university degree that she had been pursuing for several years in respect to this photograph:

*Schooling for me is so important to this disease because I feel like it's my strongest form of insurance long term, is to get my degree, because I've taken so long to get it that I can't move up at work until I get my degree. And so it's always driving me because I want to get it as quick as possible so that I can make sure that I end up getting a job that pays me more or that I enjoy more. Like I don't want to have to do a job the rest of my life just because it's the only job I can get. You know? And, so, school I can't emphasize how important it is for me.*



This photograph and quotation demonstrate the value that a university degree holds for Sandra, especially since being diagnosed with MS has introduced uncertainty regarding her future capabilities; particularly, Sandra insinuated that having a degree will help to ensure employment that does not involve physical activity, which is crucial in the event that her illness progresses and results in physical limitations.

In addition, Stacey discussed how the illness experience had led her to seize new opportunities, including pursuing a new career path and purchasing a store with her husband. She



recalled: *Cancer has made me brave; Before cancer, I was frightened to try new things [or] take risks. Now I push myself to do what makes me happy... no matter how much it scares me.* The greater sense of urgency to achieve her goals that Stacey expressed was linked to her realization that her life maybe shorter than she formerly believed, as discussed in Chapter Six. Thus, moving on for Stacey did not merely involve returning to former roles, but also entering new ones and challenging herself to fulfill her goals.

Aurelie shared Stacey's feelings of urgency to achieve goals and seize new opportunities as a result of the illness experience. She included this photograph of her atop a pyramid of sand on a trip to Namibia to illustrate her desire to carry on with life and realize her aspirations, which she described by saying:



*Life goes on, as I said, and as we know that we can die, [individuals with brain tumours] have more risk to die before others, so we have to achieve our dreams or our goals before, as soon as we can, and we don't pay attention now to things that can stop us, we are stronger... It's like being on the other side of the mountain... It's seeing life differently.*

Thus, the realization of her mortality instilled Aurelie with the motivation to achieve her goals.

The urgency expressed by Aurelie and Stacey because of the recognition of a potentially



shortened life course corresponds to the findings of research on cancer survivors, in which illness was found to bring about reflection on how time is spent and a greater focus on the present (Rasmussen & Elverdam 2007).

The comments cited in the preceding few paragraphs highlight how participants moved on with life despite the limitations and uncertainties introduced by illness. I observed that in many of the participants' stories they sought to characterize illness as an interruption, something that was experienced temporarily and followed by a resumption of their past social identity (Charmaz 1991). Such a characterization also corresponds to the 'restitution narrative type' identified by Frank (1995), which he proposes is the most commonly encountered type of story about illness. Restitution narratives are stories in which individuals become ill, are treated, and return to a state of good health (Ibid), and correspond to Parsons' (1951) theory of the sick role (Lupton 2003, p.7). Although the serious illnesses by which participants were affected are chronic or have ongoing implications, all of the them told stories of returning to or continuing on with previous roles in order to convey that they are carrying on with life in spite of illness, even if their health had not been restored. This observation corresponds to Frank's suggestion that individuals tell restitution narratives because they desire recovery, and because they think that other people want to hear such stories. Thus, participants portrayed themselves as moving forward in their life course trajectory, although this trajectory may have shifted somewhat due to the illness experience.

In addition, participants' stories about moving on with their lives reflect an approach to illness identified in existing research on individuals with chronic illnesses. Specifically, Hay (2010) conceptualized the "John Wayne Model", which refers to an individual who demonstrates "qualities of strength, activity and determination in adversity" (p.262). Thus, individuals who



adopt this approach to illness emphasize their productivity and ability to fulfill socio-cultural expectations in spite of illness, such as continuing with employment and other social roles, which ultimately ascertains their moral worth (Ibid). Therefore, the young women in this study may have sought to demonstrate such “John Wayne”-like characteristics in their discussions of illness in an effort to portray themselves in a positive way and to highlight their value as productive members of society – they will ‘do’ as much as they can in the time that they have left. As such, participants’ efforts to move on with their lives may reflect their desire for social acceptance following experiences that have made them feel like de-valued members of Western society.

#### *7.2.4 Summary*

This theme highlights various aspects involved in making sense of illness for the young women in this study. Although participants were unable to explicitly outline how they made sense of illness, their stories about illness offer insight into the sense-making process and different ways in which they understood their experiences of illness. First, I described how several participants considered possible aetiologies of illness, which reflects their attempts to make sense of illness at a superficial level. Specifically, participants contemplated the possibility that illness was an abnormality present since birth and/or the result of genetics. Such explanations seemed to provide comfort to participants by negating personal responsibility for illness. Interestingly, participants preferred such biomedical explanations of illness despite that they did not necessarily reinstate control over the body or predictability.

In addition, some participants talked about how diet, exercise and stress could have been contributing factors. For the most part, participants defended their lifestyle choices as evidence that they were not personally responsible for illness. However, a few participants believed that



stress played a role in the aetiology of illness, which helped them to make sense of why illness had happened. Although most participants did not want to appear personally responsible for their illness, identifying something that could be controlled also offered a concrete cause of, and way to deal with, illness for some participants. In addition to considering possible aetiologies, participants sought to make sense of illness by trying to find meaning in their experiences. Although a definitive meaning in the illness experience was hard to identify for several participants, most of the young women believed that they had or would eventually find meaning in their experiences, highlighting the dynamic and contextual nature of the meaning-making process (Charmaz 1991). Discussion of their realizations about themselves and others draws upon “the quest” narrative type identified by Frank (1995), in that the illness experience was characterized as offering newfound insight. As such, finding meaning in illness involved participants’ engagement with socio-cultural discourse related to illness, and thus highlights “the intersection between culture, meaning and experience” (Thomas-MacLean 2004).

Although participants’ lives were disrupted by the diagnosis of a serious illness, many of the young women sought to move on from the illness experience, even if the illness by which they were affected was chronic or could potentially recur. Moving on involved the realization that the illness experience could have been more detrimental to their lives and comparison of their situation to that of others affected by illness. As a result, participants came to see themselves as fortunate in that illness had not imposed severe limitations and they were able to continue on with many of their former activities. Moving on also involved attempts to attain a sense of “normalcy” in their lives (Miedema et al. 2007) through the resumption of past roles and responsibilities or the assumption of new ones. Thus, participants’ life course trajectories were often revised and took on new directions. Specifically, a few participants emphasized their new



found willingness to seize opportunities that they encountered, as well as the greater urgency they felt to fulfill former goals.

This theme highlights some of the ways that the young women attempted to make sense of the disruptions that illness brought about in participants' lives. As mentioned previously, participants were involved in an ongoing process of making sense of illness and found it difficult to communicate a definitive explanation for, or meaning of, illness. However, considering possible aetiologies, finding meaning in the illness experience, and moving on with life were three components of the sense-making process. Although participants typically identified a scientific explanation for illness, they also recognized personal and interpersonal outcomes of illness, and how these affected their current life and future. Therefore, making sense of illness occurred at different levels and was a dynamic process. In explicating this process for these young women, I demonstrate that making sense of illness was related to the timing in their life at which illness occurred; in particular, illness profoundly affected the future that participants formerly envisioned, and provided new motivation and direction for the achievement of their aspirations.

### **7.3 Discussion of the Research Findings**

Through the study of 10 young women's lived experiences of serious illness, I sought to better understand what it is like to be seriously ill during young adulthood. In Chapter Five, I demonstrate how the onset or discovery of illness was unexpected and symptoms were often minimized by participants. In other words, upon encountering initial signs of illness, several participants considered the possibility that they had come down with a minor health ailment or denied the presence of illness, rather than perceiving their bodily experiences as evidence of



serious illness. Thus, many participants drew upon ‘typifications’ (Rehorick 1986) or ‘interpretive resources’ (Holstein & Gubrium 2007) in an effort to understand their unfamiliar bodily state. Two participants (Nicole and Aurelie) experienced a sudden onset of illness in the form of a seizure and received immediate medical care, negating time to reflect on their initial symptoms. Although each participant’s initial encounter with serious illness was unique, the young women shared the experience of trying to make sense of an altered bodily state and the impact that this could have for their lives. Further, participants’ descriptions of the onset of illness highlight how the ‘absent body’ came to the forefront of their awareness because of its dysfunction (Leder 1992, cited in Nettleton 2001, p.53).

Following the receipt of health care services and medical testing, participants received a diagnosis and treatment. However, the path to diagnosis was not linear, with some participants experiencing delays in diagnosis. While several participants had their concerns downplayed by health care providers, signs and symptoms of illness in two participants were not recognized as such for some time. One of these participants (Laura) believed that her age was a big factor in how signs of illness were perceived, a suggestion that corresponds to one study’s finding that delayed diagnosis is common for young adults with cancer because health care providers and young adults themselves do not suspect cancer to be likely (Miedema et al. 2006). Other participants (Melissa, Nancy, Melanie) who encountered ambivalence from health care providers persisted in having their symptoms investigated because of fears that serious illness was a possibility. In these cases and others, diagnosis offered relief for some participants (i.e., Melissa, Elizabeth, Melanie) who wanted their health problems to be identified and treated as quickly as possible. The absence of a life-threatening illness for two participants (Sandra, Melissa) also contributed to ‘diagnostic relief’ (Charmaz 1991).



Again, while illness had varying implications for the young women who participated in the study, each participant faced a similar challenge of trying to manage the implications of illness for their body and reconcile illness with their identity. Some participants (Aurelie, Stacey, Melanie, Laura) underwent surgery to treat illness which left them with an altered body. Other participants (Nicole, Sandra, Nancy, Melissa, Elizabeth) experienced their body in a new way as they struggled to understand its perceived malfunction. One participant's (Leanne) experience was distinct in that illness had left her with a body that was incomparable to her previous and current physical state, which was gradually restored during the recovery period. Thus, participants' relationships with their body were highly affected by the illness experience and illness was sometimes experienced as a betrayal by the body, similar to what has been proposed by Thomas-MacLean (2008) in a study of female breast cancer survivors. Coming to terms with illness therefore involved a process of integrating the altered body into self identity. Participants' position in this process was dynamic and varied immensely, often in respect to the time that had elapsed since diagnosis, the ongoing threat of illness, and/or the extent of physical changes.

Further to negotiating an altered relationship with the body, participants faced limitations in what their body could do as a result of illness. Limitations included both the inability of the body to perform as it used to, as well as restrictions arising from potential risks related to illness. These limitations resulted in changes in everyday tasks, as well as their leisure activities and social lives. For example, with respect to their everyday lives, some participants talked about pain and difficulties with vision and mobility, and noted that activities such as walking, childcare, opening doors, and driving had become problematic. Further, some participants could not participate in leisure pursuits such as exercise, dancing, horseback riding, or socializing at the bar with friends. While the physical component of these limitations was difficult to manage,



participants focused more on the psychosocial aspects of their limitations and the difficulty that they experienced in trying to come to terms with no longer being able to do what they had in the past. Thus, participants were required to re-negotiate their expectations for themselves as is commonly the case for individuals affected by illness and disability (Charmaz 1991). Furthermore, having such limitations was hard to reconcile with their identity as a young adult, especially given the common characterization of young adults as healthy, invincible and having many years ahead of them (Exley & Letherby 2001; Hilton et al. 2009; Lee 2001; Miedema et al. 2007).

In addition, many participants talked about the implications of illness with respect to discourses of femininity and feminine social roles. According to Stoppard (2000), discourses of femininity refer to “sets of shared cultural beliefs and practices that construct the meaning of ‘woman’, what it is to be a woman, and experiences of subjectivity in women” (p.23, cited in Lafrance & Stoppard 2006, p.310). As such, participants referenced and drew upon socio-cultural constructions of femininity in their discussion of illness and its implications for their well being. For example, Stacey, Melanie, and Laura were particularly cognizant of the threat that the loss of a breast had for their appearance and feminine identity, given the emphasis placed on breasts in contemporary Western society. Thus, these participants were more conscious of their appearance which required them to alter their style of clothing to hide any perceived ‘abnormalities’. Aurelie also experienced changes to her appearance in the form of a scar and hair loss, which also required negotiation so as to not be perceived as different.

Several participants also experienced pronounced disruptions to their social roles because of illness that threatened their feminine identity. Most evidently, the majority of participants talked about lost or potentially lost opportunities to have children because of the implications of



illness; thus, illness greatly threatened their assumption of the motherhood role, a role that is closely tied to femininity (Exley & Letherby 2001). In Melanie's interviews, maintaining her role as a mother during the illness experience arose as an issue of central importance so that she would not be perceived as a 'bad mother'. Specifically, her construction of herself during the illness experience draws on traditional gender roles propagated by discourses of femininity (Stoppard 2000, cited in Lafrance & Stoppard 2006). Aurelie was the only participant who resisted such discourses of femininity by indicating that she was not planning to have children and therefore was not concerned about possible limitations resulting from treatment. Similar to Melanie's reported efforts to maintain a care giving role in spite of illness, other participants also engaged with discourses of femininity in their descriptions of how they negotiated the implications of illness for their ability to care for and support family members and partners. For example, participants' comments about not being able to perform domestic tasks or fulfill care giving roles, either during the illness experience or in the future, reflect their struggles to manage expectations of femininity in spite of illness.

For those who required hospitalization or extensive treatment, many aspects of life were disrupted. For example, Stacey related that she experienced her initial diagnosis as something that she did not have time for in her busy life. Also, missing out or having to press pause because of illness were issues that repeatedly arose in the interviews with participants. For example, participants talked about not being able to follow through with previous plans because of illness (Sandra, Laura), planning their time around treatment (Aurelie, Stacey), and missing out on events in the lives of friends and family (Leanne). Leanne and Aurelie in particular reflected on the time that they lost due to hospitalization and treatment, emphasizing their desire to return to



their previous activities. Thus, illness was disruptive in that it affected everyday routines and plans for how their time was spent.

In addition to affecting time in their everyday lives, serious illness also was disruptive to participants' expectations for the future. While I draw upon Exley and Letherby's (2001) term 'disruption' to capture the wide-ranging effects that illness and its resulting losses had on participants' life course and self identity, I also wish to recognize that the impact of illness was much more profound than this term may communicate. In one sense, illness brought about uncertainty and the realization of mortality for many participants, who came to perceive time as being more fragile than previously. As a result, some participants worried about the impact that their uncertain futures had on their loved ones, while others felt a greater sense of urgency to realize their aspirations. As such, illness threatened the taken-for-granted assumption that they had many more years in their life course ahead of them. In another sense, participants experienced losses or potential losses in relation to the realization that their life course may not be as long as they previously expected. Laura summed up the difficulty that this posed, suggesting that it was unfair that she and others like her may not have the opportunity to have experiences that others are able to. As such, the experience of serious illness during young adulthood constituted an upheaval of much of what was taken-for-granted in participants' everyday lives or their expectations for the future.

Overall, illness was largely experienced by participants as something that was inconsistent with their 'aged identities' (Hockey & James 2003) and was happening at the wrong time. In particular, illness and its implications were perceived as being in conflict with the common characteristics of the young adult life stage. For example, the bodily experience of illness and the side effects of treatment led some participants to feel older, best articulated by



Stacey who described her menopausal symptoms as like living in her mother's body. Illness also shook some participants' youthful optimism, and sometimes brought about growth and maturity that was seen as more common in older individuals. Other participants, such as Nicole and Leanne, viewed their diagnoses as problematic to reconcile with their young adult identity because they were more prevalent in younger individuals. Thus, illness made many participants feel abnormal and "off time" (B.R. Williams 2004) in a number of ways.

Participants also portrayed illness as being detrimental to the fulfillment of social roles typical to young adulthood, such as obtaining an education, securing employment, establishing a long term relationship, and having children (Lynam 1995). In particular, Melanie was required to adapt her role as a mother to the limitations brought about by illness, while other participants, including Laura, Nicole, Sandra, and Nancy, considered the potential impact of illness and medication on their chance of having children. Several participants also talked about illness in relation to the setbacks that it brought about in their education and career paths. For example, illness required some participants to take time away from work or university, which threatened the achievement of their goals and had lasting implications for the future. The importance of education and work to the young women's identities was evident in all of their stories of illness, as many sought to continue or resume these roles following diagnosis or intensive treatment. However, illness also contributed to changes in education or career paths, and motivated some participants to become interested in health and caring professions. Thus, the illness experience had a lasting impact on participants' social roles and envisioned future because it required the re-negotiation of their current roles and expectations for future roles in light of illness and its implications, which included both setbacks and newly emerged interests.



Furthermore, illness had implications for participants' relationships with others. For example, many of the young women relied on family members, partners, friends, and similar others for support during the illness experience. Some of the young women described an increased closeness with family members and friends because the illness experience brought about greater appreciation of the time that they had together. On the other hand, a few of the participants felt that their relationships with certain individuals had become problematic during the illness experience, as communication was difficult or support needs had gone unmet. In particular, three of the young women (Stacey, Laura, Nancy) perceived their parents and/or mothers to be unsupportive at times, which is contradictory to existing research that emphasizes the value of family at times of illness (Pierret 2003; Steinglass 2000). This finding raises questions about how young adults and their parents can manage the provision of support while also respecting their independence from the family of origin and parents' difficulty with watching their child experience illness. Illness also generated guilt in many participants who were concerned about the burden that their illness and its potential implications had for loved ones. An existing study has reported that women with ovarian cancer also experience great concern over the impact that their illness had on partners and children (Howell et al. 2003), suggesting that such worries may be a common experience for women affected by serious illness.

In addition, illness led some participants to be more reliant on family members, partners and friends, thus threatening their sense of independence, which was newly established for some of the young women. Independence has been highlighted particularly as an issue for young adults with cancer (see for example, Grinyer 2007), and is clearly a concern for young women with other types of illness as well. For example, Leanne, Melissa, and Elizabeth each spoke



specifically about their reliance on others resulting from illness, while other participants more implicitly described how they depended on others for various types of care and support. Elizabeth explicitly drew a connection between independence and the invincibility that she associated with her youth prior to being diagnosed with depression. In doing so, she communicated that becoming ill made her realize that she was not invincible and therefore could not necessarily maintain independence at all times, particularly during a crisis such as illness. Thus, while individuals of various ages may struggle with the dependence on others that serious illness often brings about (as evidenced in the research of Charmaz (1991)), independence may be experienced in a different way by young adults for whom independence from the family of origin is newly established or in the process of being established. Further, independence may be equated with broader characterizations of young adults as invincible and free to control their lives as they see fit. As such, illness threatens young adults' independence in that it may hinder their movement away from their family of origin and ability to lead the lives that they have imagined and sought out for themselves.

Despite the upheaval caused by illness for participants, they made sense of their experiences through: considering possible aetiologies of illness, finding meaning in the illness experience, and attempting to move on with their lives. In doing so, participants drew upon dominant discourses and cultural resources as ways of making sense of illness (Lupton 2003), thus engaging with socio-cultural constructions of illness as conveyed by science/medicine, the media/pop culture, and in social interactions. In particular, some participants' reflections demonstrate a preference for biomedical explanations of illness in that this type of explanation offered a rational or logical explanation for why illness occurred, although several participants also considered possible environmental and lifestyle factors in the causation of illness, including



injuries, past medical procedures, stress, and other lifestyle behaviours. The underlying motivation for participants to determine the likely aetiology of illness was twofold: one, it provided an explanation of why illness had occurred at a superficial level, and two, it determined whether participants were personally accountable for their illness. Personal responsibility for illness, and the stigma resulting from engagement in risky behaviours or failure to take preventive measures, reflects a moral component of the experience of illness. Specifically, illness emerges as a sign that individuals may have failed to engage in proper health behaviour, thus calling into question their moral character. Thus, participants' preferences for scientific explanations of illness may be reflective of their desire to absolve themselves of personal responsibility for illness and defend their moral character (Lupton 2003).

In addition, participants also drew upon dominant discourses and cultural resources related to the meaning gained through the illness experience in order to make sense of their experiences. As such, some participants spoke about learning about themselves and others because of illness, and developing new priorities. Such sentiments are evident in the stories of other ill individuals, especially those portrayed by the media. Kleinman (1988) refers to the insight and moral lessons gained through pain and suffering as the "inner moral meaning of chronic illness" (p.55). However, not all participants communicated that the illness experience held meaning for them, as they were still in the process of coming to terms with the immediate implications of illness and the uncertainty of the future.

Participants also spoke of their hopes for the future in spite of illness and the uncertainty that they continued to face. According to Charmaz (1991), over time and through adjustment to illness, ill individuals find that their time perspective expands to go beyond the present to include the future. This shift is evident in the stories told by several of the young women who sought to



come to terms with illness and its implications and move beyond illness. For several of the participants, moving on with life involved relativizing or downplaying their illness, and revising their expectations for themselves and the way that they envisioned their life course. Participants also came to achieve a sense of “normalcy” in their lives through the resumption of past roles or the assumption of new ones, although this new “normalcy” did not necessarily mirror their lives before illness (Miedema et al. 2007) because their lives had been forever changed by illness. Some participants gave as an example the greater urgency or importance placed on achieving their aspirations, as illness brought about the realization that their life course could be dramatically shorter than previously believed. As such, illness was experienced as a biographically disruptive in that it brought about the re-examination of expectations for the future (Bury 1982) and challenged participants’ past association of illness with old age (S.J. Williams 2000).

For participants, the future shifted from being a certainty prior to illness to an uncertainty because of illness, and sometimes back again after the initial crises brought about by illness were managed. This shift back toward a sense of certainty demonstrates the hope that emerged as participants adapted to illness and sought to integrate it into their identity. Charmaz (1991) refers to this stage in the experience of illness as “mapping a future”, which involves a shift from a focus on the present during crisis to a focus on the future following crisis (p.190). However, participants were at various points in this process and expressed varying degrees of hope for the future in comparison to others and at different points during their interviews. For example, Melanie felt confident that she was a breast cancer survivor but remained concerned about the possibility of a recurrence, while Nancy was fixated on the symptoms that she continued to experience and struggled with many unknowns, while other participants fell somewhere in



between. Although time since diagnosis somewhat influenced the point at which participants were in the process, Stacey's experience of three breast cancer occurrences highlights how time perspectives continue to shift over time. Thus, the experience of serious illness during young adulthood required that participants manage disruptions to their expectations for the future and attempt to incorporate a potentially altered life course into their self identity.

Similar to other ill individuals, the young women in this study experienced illness as a disruption to their embodied selves and time perspectives. However, illness-related disruptions were contextualized by the time in the life course at which they occurred, thus making the experience of illness for participants unique to those of older adults and adolescents.

Specifically, I observed that the young women faced an altered body or relationship with the body as a result of illness and its treatment. Thus, the young women entered into an unfamiliar bodily state that did not correspond with their young adult identity or expectations for this time of life. In addition, participants experienced a shift in their time perspective, referring to their "ideas, beliefs, and views about the content structure, and experience of time" (Charmaz 1991, p.170). Time was a pervasive aspect of their stories – they were "off time" (*the wrong time*), time sped up (*a blur*), time slowed down (*dragged on*), time stood still (*press pause*), time was lost (*missed out*), and time was unpredictable (*uncertain*), and time was scarce (*urgent*). Therefore, I observed that illness affected participants' experiences of their lived body and lived time (van Manen 1990), and required them to make sense of these changes in order to move on with their lives.

As a whole, the thematic analysis of the young women's experiences of serious illness reveals various ways that participants sought to and struggled with coping. Coping refers to the dynamic and ongoing process of dealing with difficult life situations that involves both cognitive



and behavioural efforts to deal with their own and external demands (Folkman and Lazarus 1988, cited in Kyngas et al. 2000, p.7). As much research has explored coping with respect to illness, my intent is not to outline a specific theory of coping. Rather, I wish to situate key aspects of coping that emerged in the young women's stories of illness in existing research on young adults affected by serious illnesses. In doing so, I elaborate our understanding of how young adults cope or struggle to cope with serious illness and its ensuing disruptions to everyday life and expectations for the future.

As reported by Kyngas et al. (2000) and Miedema et al. (2007), one way that young adults with cancer sought to cope with a cancer diagnosis involved gathering information about illness. Such a strategy may be particularly valued because it offers an active way to cope and allows young adults to feel in control of some aspect of their life. Additionally, learning more about illness can help young adults to understand why it occurred, improve self confidence, and encourage positive thinking in some cases (Kyngas et al.). Similar to existing research, several participants in this study benefited from coping with their diagnoses through researching illness. However, some participants also experienced negative implications of researching illness, as discussed in Chapter Five; particularly, negative or contradictory information was challenging for some young women to deal with, while a lack of relevant information could also be demoralizing. Thus, negotiating information about illness was complex and both positively and negatively influenced the coping process.

Also similar to the findings of Kyngas et al. (2000) and Miedema et al. (2007), the young women in this study sought social support as a strategy to cope with illness. As demonstrated in Chapter Six, the negotiation of relationships and social support was a central aspect of participants' illness experiences. While there is widespread recognition of the importance of



social support to successful coping, it is also important to mention that a perceived lack of support could have negative implications. For instance, those participants who were unable to access adequate information on illness or treatment (Nicole, Nancy, Elizabeth) or experienced unsupportive interactions with health care providers, family members, or friends (Nancy, Melissa, Elizabeth, Stacey, Laura) were required to seek support from other sources. For some of these young women, alternative sources of support often fulfilled support needs. On the other hand, some of participants' support needs remained unmet and contributed to difficulty with coping. Specifically, Nancy and Melissa received inadequate support from health care providers (at least initially) that could not be supplemented by support from family members or friends. As a result, these two participants experienced: uncertainties regarding diagnosis and treatment, difficulties with managing symptoms, and a struggle to make sense of their experiences. Thus, the experiences of these two participants show that a perceived lack of social support, particularly from health care providers, may contribute to difficulties coping with illness.

The young women also sought to cope by striving for a sense of “normalcy” in their lives through the resumption of everyday roles and activities, as was the case in existing studies (Grinyer 2007; Kyngas et al. 2001; Miedema et al. 2007). The desire to move on with life in spite of illness was not a simple or linear process, as some participants continued with social roles and activities amidst the disruptions caused by illness, whereas others' everyday lives slowly became more ‘normal’ after a period of great disruption. However, as noted above, “normalcy” did not necessarily involve a past version of everyday life (Miedema et al.), often because illness had introduced physical and psychosocial changes. For example, participants' discussions of uncertainty and mortality highlight how life could never return to the way it was prior to diagnosis, as did stories of integrating medication regimens, adjusting to losses or



limitations, and managing changes in embodiment. Furthermore, the dynamic and ongoing nature of the illness experience meant that a new sense of ‘normal’ was difficult to attain, a finding also reported in research about young people with sickle cell disorder (Atkin & Ahmad 2001). Thus, while existing research has highlighted the desire for “normalcy” by young adults facing serious illnesses, participants’ experiences call attention to the idea that this is not an easy feat, even when they are able to continue on with many aspects of their lives.

In order to deal with disruption that illness caused to the taken-for-grantedness of their everyday lives prior to illness, many of the participants sought to put their experiences into perspective through “relativization.” Relativizing illness involved comparing their situation to other potential experiences or other individuals affected by illness (i.e., being in a perceivably worse situation). This relativization allowed participants to view their experiences in a more positive light, similar to sentiments expressed by other ill individuals (e.g., Atkin & Ahmad 2001; Bowes et al. 2002; Finlay et al. 2001). While many of the young women expressed feelings of isolation and abnormality in comparison to other young adults, they also recognized that the challenges that they faced were relatively minimal when compared to what could have happened or what other individuals face. As such, relativization was a common coping strategy adopted by some participants and likely a sign of successful adaption to illness. However, not all participants adopted such a coping strategy. Two of the participants who did not engage in relativization, Nancy and Melissa, were currently struggling to manage their symptoms and make sense of illness, and thus had not yet put their experiences in perspective. The other two participants who did not discuss relativizing illness, Leanne and Elizabeth, described their illness experience as having ended, suggesting that relativization may no longer be necessary when health has been restored and illness-related vulnerabilities fade from consciousness.



The above examples demonstrate certain aspects of the coping process for the participants of this study. While the young women adopted various other coping strategies, such as humour, denial, or writing about their experiences, these examples highlight common strategies for coping adopted by many participants. In addition, I draw attention to some participants' struggle to cope, as not all of these strategies were beneficial or available to all participants. Although it is important to recognize coping strategies successfully adopted by participants of this study and in existing research, the identification of aspects that are problematic to coping is also necessary in order to improve the support available to young adults affected by serious illness and assist with successful coping. Next, I outline specific implications of this research for the care and support of young women affected by serious illness.

#### **7.4 Implications for Health Care and Support Services**

Based on the data and my analysis, I have identified a number of implications arising from this research study that may be pertinent to the provision of health care and support services for young adults with serious illness, and young women more specifically. Foremost, it is crucial for individuals providing health care and support services to recognize that young adults affected by serious illness will have both similar and unique concerns to other ill individuals. I have given several examples throughout Chapters Five and Six that highlight participants' concerns that reflect what has been reported in existing research on illness experiences. However, I have also sought to outline how these issues may have different implications for young women because of their position in the life course. Thus, socio-cultural expectations for the young adult life stage influenced the way that participants experienced illness-related issues. For example, young



adults may experience physical limitations and other restrictions resulting from illness as an immense loss in the event that they affect their ability to carry out former activities or bring about changes in their social lives; on the other hand, older adults may already have experienced a gradual decline in their physical capabilities as part of the aging process or have expectations of such an occurrence. As well, the diagnosis of a serious illness during young adulthood may be the first time that young adults have encountered illness and, therefore, they may lack the coping skills that older individuals possess because of their greater familiarity with illness (Politi et al. 2007).

In addition, young women affected by serious illness may experience an altered relationship with their body and come to view their body as inconsistent with their identity as a young adult. For example, physical changes in the body and appearance resulting from illness and its treatment may have distinct implications for young women because of their life stage. Specifically, mastectomy or hysterectomy surgeries may compromise young women's ability to bear and breast feed children, as can certain treatments and medications, an issue that was identified by a number of participants. The loss or potential loss of certain female reproductive organs also required negotiation with partners and had implications for self identity and appearance, particularly in interactions with others. As well, illness brought about changes in the relationship that participants had with their bodies, as illness generated feelings of distrust, betrayal, and confusion. Thus, illness was perceived as a loss of control as participants' bodies came to dictate their lives. As a result, the young women sought ways to re-gain control in their lives through: obtaining information about illness, being involved in decisions about treatment, and/or resuming past social roles.



Participants' stories of illness also highlight the need for young adults to revise their envisioned life course as a result of illness, particularly to account for the possibility that life could be dramatically shorter than previously expected. Such a realization may lead young women to experience illness as bringing about losses and/or potential losses in their envisioned future. However, some participants also interpreted illness and the threats that it posed to their expectations as an impetus to more urgently pursue their aspirations. Thus, these young women experienced illness as a threat to their envisioned life course as older adults may also, but the losses or potential losses were perceived as greater because, as young women, they had yet to have opportunities to achieve many of their goals and dreams, particularly with respect to having children. Furthermore, young adults may have unique concerns in comparison to adolescents who still live with parents and rely on them financially, and who are less likely to have long term partners or children.

Accordingly, young adults may benefit from the recognition by individuals involved in health care and support provision of their position in the life course and the distinct issues that they face because of serious illness. In particular, similar others may be particularly important sources of support for young adults, as shown by the experiences of the participants. Although some participants valued support from individuals of a variety of ages affected by the same illness, there was overwhelming evidence that the young women appreciated or would appreciate the availability of support from other young adults affected by illness. While it was reported that peer support for young adults with cancer was presently available, few of the other young women had found similar others with whom they could discuss practical concerns. This finding suggests that support organizations should consider the creation of or better publicity for peer support services that engage young adults as peer supporters, as has reportedly been done by the



Canadian Cancer Society. Peer support offered by similar others in a group setting or through the telephone or Internet may help to lessen young adults' feelings of abnormality and isolation that can result from the illness experience. Further, comments made by participants provide evidence that young adults with various forms of serious illness may face similar psycho-social issues related to their life stage and thus may relate to one another despite having different medical concerns; however, young adults may prefer access to support from similar others who fit into the same broad category of illness (chronic vs. life-threatening, physical vs. mental, cancer vs. autoimmune, etc.). Therefore, the formation of peer support services for young adults affected by a variety of illnesses would be of benefit, although some consideration of different types of illness may be necessary.

As the above discussion highlights, sensitivity to life stage is required by individuals involved in providing health care and support services to young adults, who may experience illness as disruptive to many aspects of their life and envisioned future. Further, health care and support providers should acknowledge that illness can thrust many young adults into an unfamiliar world in which they experience an altered bodily state and a lack of knowledge of how to cope with being ill and treatment or medication regimens. The recognition that young adults may experience unique losses or potential losses from others affected by serious illness is also crucial to meeting the needs of this population. For example, the realization of mortality may bring about the realization of lost opportunities or feelings of abnormality, rather than existential concerns. By learning about the experiences of the participants of this study and the specific issues that they face because of illness, health care and support providers may be better equipped to understand their clients and offer more sensitive and appropriate care and support.



## 7.5 Methodological Reflections

In carrying out this study, I gained insight into the use of qualitative research, and phenomenological interviews and a modified version of photovoice in particular, to study the social experience of illness. Foremost, while qualitative research does not allow for generalizability in the same way that quantitative research does, using a qualitative approach enabled access the essence of what it is like to be seriously ill during young adulthood from point of view of the 10 young women who participated in the study. As such, the result was rich and detailed interview data that highlighted experiences and issues that the participants felt were significant. While these experiences and issues may not be shared by all young women facing a serious illness, the similarities that emerged within the data suggest that the research findings may be pertinent to some other young women. Particularly, the occurrence of illness during young adulthood may introduce disruptions and losses/potential losses related to embodiment, social roles and relationships, and expectations for the future similar to those experienced by the participants of this study.

While efforts were made to recruit a diverse group of participants, the successful accomplishment of this aim varied. As mentioned previously, participants shared similar socio-economic characteristics, with all having at least some university education and a few having graduate level education. Additionally, the sample was not ethnically diverse, with none of the participants indicating a minority status. I offer possible explanations for this lack of diversity in Chapter Three, although the use of a snowball sampling approach can partly be attributed. Thus, future research in this area should focus on young women from more diverse backgrounds in order to determine similarities and differences across socio-economic and ethnic backgrounds. However, the study sample included participants from across the range of ages selected (21 to 37



years), one of whom was a rural resident, one that resided just outside of an urban centre, and eight living in one of the two large urban centres in the province. Thus, some diversity within the sample was achieved.

One perceived drawback that arose during the analysis of the research data was related to the sheer quantity of data generated through the in-depth interviews. I completed 18 interviews with the 10 participants, each of which ranged from 45 to 120 minutes, resulting in hundreds of pages of interview transcripts. While this quantity of data provided great insight into the illness experiences of participants, I found it difficult to include all of the topics broached in my analysis. Consequently, I focus on the broad themes relating to: the embodied experience of illness, the disruption caused by illness to the life course, the need to negotiate relationships and support in light of illness, and the process of making sense of illness. Within these broad themes, I highlighted several sub-themes, some of which were not relevant to all participants. For example, the experience of mental illness may differ from physiological illness, despite that mental illness can also have physical implications, and vice versa. However, shared experiences also emerged for many of the young women across different types of illness in relation to the young adult life stage. As such, I recognize that there were certain experiences that were not shared by all participants, although the similarities and differences observed are equally telling and offer insight into how various personal and socio-cultural factors influence the experience of serious illness.

The completion of this research study also provided valuable insight into the use of a photovoice approach to the social study of illness. From my own perspective, I believed that the photovoice project was beneficial: to recruitment by garnering the attention of participants, to the participatory aspect of the research, by offering greater insight into participants' experiences, by



allowing participants the opportunity to reflect on their experiences and be creative, and by eliciting stories. However, I would suggest that the use of a photovoice approach be considered carefully by other researchers because of the additional complexities that it adds to the research process. In addition to practical concerns about technology, I observed that some participants were unsure of what to take photographs of and struggled to express themselves visually. Others found it difficult to access the subject(s) that they wished to photograph, and therefore were not able to take the photographs that they envisioned. On the other hand, some participants were able to manage this issue by verbally describing the photographs that had not been taken, or bringing pre-existing photographs to the interview. Interestingly, one participant showed me a photograph of herself while in the hospital at her initial interview, but did not include this photograph in the study. In addition, some photographs that participants took are not included in this dissertation because photograph release forms were not returned for the individuals who appear. Finally, one participant did not complete the photovoice project because of time constraints, which raises the issue that the time and effort required to complete the photovoice project may be more than some individuals can or are willing to invest.

Perhaps more importantly, participants also shared a number of reflections on their participation in the photovoice component of the study. Some participants were particularly appreciative of the opportunity to tell their story of illness in this way because they valued the creativity involved and the ability of photographs to show the complexity and human side of illness. Several participants discussed how the photovoice project offered a more personal aspect to the research. Consequently, participants talked about the need for greater reflection in comparison to interviews because of the time involved in deciding what to photograph, which was seen as a benefit of the approach, but also brought up emotionally difficult memories for a



few participants. Thus, researchers should weigh the potential benefits of the research with the possibility of emotional harm to participants prior to using a photovoice approach to study sensitive topics. However, the majority of feedback from participants on their participation in the photovoice project was positive. Additionally, practical considerations identified by participants were related to: poor weather, not having a camera when an idea for a photograph arose, difficulty taking photographs retrospectively (i.e., post-treatment), and gaining consent from individuals appearing in the photographs. Finally, some participants commented that it was difficult to translate their experiences into photographs, even though these participants still completed the photovoice project.

## **7.6 Conclusion**

In this dissertation, I describe a study carried out in order to explore the experiences of young adult women affected by serious illness. The purpose was to gain a better understanding of what it is like to be seriously ill during young adulthood and the specific issues that young women face because of serious illness. Although this research was exploratory and had a broad focus, my interest was to learn more about how the timing of an illness diagnosis affects the ways in which illness is experienced and made sense of. Serious illness was unexpected and brought about disruptions in the young women's sense of embodiment, everyday lives, relationships, and expectations for young adulthood and the future. Thus, I observed that participants' age and/or life stage at the time of diagnosis was influential on how they understood their experiences. Further, participants engaged with socio-cultural constructions of health, illness, and the life course in order to make sense of being ill at this time in their lives. In



addition, participants' experiences of serious illness were contextualized by discourses of gender, as the young women also negotiated socio-cultural constructions of femininity and feminine social roles in their discussions of illness.

This study contributes to the body of literature on illness narratives through its specific focus on how young women make sense of their experiences of serious illness, as minimal attention has been paid to young women with illnesses other than cancer. Additionally, existing research has not sought to identify similarities in the experiences of young women with different types of illness. Further, few studies have incorporated participant-employed photography into psychosocial research on illness, and none have focused specifically on young women affected by serious illness. Subsequently, the participants' stories of illness presented in this dissertation offer insight into the complex and deeply emotional experience of serious illness during young adulthood and the processes involved in coping with and making sense of such experiences. Their stories and my interpretation can therefore serve as a means to educate and enlighten individuals involved in health care and support provision for this population, as well as academics interested in illness narratives, young adults and other individuals affected by illness or loss, and the general public.



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## APPENDIX A: Consent Form

You are invited to participate in a research project entitled **Making Sense of Illness: Young Adults' Experiences of Life-Threatening Illness**. Please read this form carefully, and feel free to ask any questions you might have.

**Researchers:** Dr. Roanne Thomas-MacLean  
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**Purpose:** The purpose of this research study is to explore the experiences of young adults with life-threatening illnesses, as well as the experiences of their family members. It is hoped that this research study will contribute to a better understanding of how life-threatening illness affects the lives of young adults and their families and of what it means to be ill during young adulthood.

**Procedure:** Young adults and their family members are being invited to participate in taking photographs that highlight significant aspects of the illness experience. Participants will then have the opportunity to talk about their experiences and the photographs they have taken in audio-recorded interviews. Interviews will last approximately 60 to 90 minutes, although participants may choose to participate in 2 or 3 shorter interviews if that better fits their preferences. Total time commitment from participants will be approximately 2 to 4 hours, but may depend on how much time participants spend on the photography portion of the study.

**Potential Risks and Benefits:** This study poses no known risks or benefits to participants. The personal and sensitive nature of the research introduces the possibility that participants may experience an emotional response as a result of talking about their illness. Participants have the right to refuse to answer any questions that they do not wish to and can request that the recording device be turned off at any time. If participants have strong emotional responses to participation in the study, the researcher will provide participants with the contact information for appropriate services available within the province. Participants may also be subject to a potential loss of anonymity and confidentiality because of the use of photography in the study. Participants who wish for their identities to remain confidential will be able to do so by choosing to use a pseudonym and by not appearing in any of their photographs.

**Right to Withdraw:** Your participation is voluntary, and you can answer only those questions that you are comfortable with. There is no guarantee that you will personally benefit from your involvement. The information that is shared will be held in strict confidence and discussed only with the research team. You may withdraw from the research project for any reason, at any time, without penalty of any sort. Withdrawal will not affect your medical care or access to health services. If you choose to withdraw from the study, any data you have contributed will be destroyed beyond recovery at your request.



**Confidentiality:** Your personal information will be kept confidential unless you choose for it to be associated with your contributions to the study. If you wish for your identity to remain confidential, only a pseudonym will appear with direct quotations from your interview(s). Personal information such as phone numbers, addresses, and organizational affiliations will be kept confidential and any information that may identify third parties associated with participants will be deleted or altered (i.e. names of doctors, family members, etc.). After your interview, and prior to the findings being reported, you will be given the opportunity to review the transcript of your interview(s) and the photographs, and to add, alter, or delete information as you see fit.

**Storage of Data:** All information collected for this study, including audio-recordings and transcripts of interviews, photographs, and contact information, will only be available to the two researchers listed above. The data will be stored in a locked filing cabinet by Dr. R. Thomas-MacLean at the University of Saskatchewan for a minimum of five years after the study is completed. After five years, if the data is chosen to be destroyed, it will be destroyed beyond recovery.

**Dissemination of findings:** The findings of this research study will be used as the basis for a doctoral dissertation, and may also appear in reports to support groups, conference presentations or academic journal articles. Participants will have the opportunity to review the data that they have contributed to the study and give their consent before it is presented or published.

If you have any questions concerning the study, please feel free to ask at any point; you are also free to contact the researchers at the numbers provided if you have questions at a later time. Please do not hesitate to contact the researchers with any questions about the research or findings. You can contact either: **Dr. Roanne Thomas-MacLean**, Department of Sociology, 9 Campus Drive, University of Saskatchewan, S7N 5A5, Phone: (306) 966-1489 or **Meridith Burles**, Department of Sociology, 9 Campus Drive, University of Saskatchewan, S7N 5A5, Phone: (306) 665-1314. This study has been approved on ethical grounds by the University of Saskatchewan Behavioural Research Ethics Board on (insert date). Any questions regarding your rights as a participant may be addressed to that committee through the **Ethics Office** (306) 966-2084. Out of town participants may call collect.

*The researchers realize that some participants would like to be identified with their stories and/or photos. This consent form lets you choose to be identified or to remain anonymous because some participants may prefer to be credited for the contributions made to this project. Through this form you may choose whether your name will OR will not appear in any report, conference presentation or publication about this study. We are also asking about your choice for identification in photos. You can choose to be anonymous, to have only your name used, or to have both your name and your identity revealed in the photos.*



I, \_\_\_\_\_, have been offered the opportunity to reveal my identity or de-identify myself in the study **Making Sense of Illness: Young Adults' Experiences of Life-Threatening Illness.**

### **Interviews:**

\_\_\_\_\_ **I would like to be identified in the study.** Identifying information may be used (e.g. your name, name of your community, personal details such as age, marital status and occupation). **I choose to have my real name used.**

\_\_\_\_\_ I would like any material used in publications to have **identifying information altered or deleted** (e.g. your name, name of your community, personal details) prior to publication. Although the data from this study will be published and presented at conferences, **I would like to be assigned a pseudonym.** The consent forms will be stored separately from the transcripts and photographs, so that it will not be possible to associate a name with any given set of responses.

### **Photographs:**

\_\_\_\_\_ I would like **photographs of myself to be used** in the study and in publications.

\_\_\_\_\_ I would like **my face to be de-identified** in the pictures that I am in for the study and in publications.

I have read and understood the description provided above. I have been provided with an opportunity to ask questions and my questions have been answered satisfactorily. I consent to participate in the study described above, understanding that I may withdraw consent at any time. A copy of this consent form has been given to me for my records.

\_\_\_\_\_

(Name of Participant)

\_\_\_\_\_

(Date)

\_\_\_\_\_

(Signature of Participant)

\_\_\_\_\_

(Signature of Researcher)



## APPENDIX B: Photograph Release Form

**Researchers:** Dr. Roanne Thomas-MacLean, Department of Sociology, University of Saskatchewan, (306) 966-1489

Meridith Burles, PhD Student, Department of Sociology, University of Saskatchewan, (306) 665-1314

**Information about the study:** We are doing a research study on the experiences of young adults with life-threatening illnesses and their family members. We are hoping to learn about how aspects of their lives are affected by illness. It is hoped that this research study will help others to better understand the experiences of young adults and their families so that they can be better supported. The research questions are:

- 1) What are young adults' experiences of life-threatening illness and how do they make sense of them?
- 2) What do young adults feel is specific to or unique about experiencing life-threatening illness during young adulthood?
- 3) What are the social support needs of young adults with life-threatening illnesses and their families?

*Participants are taking pictures to capture their responses to these questions. This form asks your permission to use the photograph(s) that you appear in as part of this study.*

**Information about dissemination of research findings:** The findings of this study will be used in a doctoral dissertation by the student researcher. Findings may also be used in conference presentations and journal articles. Common themes emerging from the interview data may be used to form a brief informative report for local support organizations for individuals with illness. No personal or identifying information will appear in this document. Data will be included in presentations and publications only after participants have given consent for its use.

I, \_\_\_\_\_, have reviewed the photograph(s) that I am in as part of the study entitled **Making Sense of Illness: Young Adults' Experiences of Life-Threatening Illness**

\_\_\_\_\_ I would like **photographs of myself to be used** in the study and in publications.

\_\_\_\_\_ I would like **my face to be de-identified** in the pictures that I am in for the study and in publications.

I hereby authorize the release of the photographs that I appear in to Meridith Burles to be used in the manner indicated above. I have received a copy of this Photograph Release Form for my own records.

\_\_\_\_\_  
(Participant's Name)

\_\_\_\_\_  
(Date)

\_\_\_\_\_  
(Signature of Participant/Legal Guardian of Child)

\_\_\_\_\_  
(Signature of Researcher )



## APPENDIX C: Interview Protocol and Guide

**Overview and Context:** Participants will consist of young adults between the ages of 19 and 39 who have been diagnosed with a life-threatening illness in the past two years and a family member who has played a role in their illness experience. All interviews will be performed by Meridith Burles, PhD student in the Department of Sociology at the University of Saskatchewan.

**Preamble:** Interviewer to describe and give background on the study, explain interview consent form, inform participants that they can choose to be assigned a pseudonym if they would like their identity to remain confidential, describe the types of questions that are going to be asked, inform participants of their right to refuse to answer any questions and their right to withdraw at any point during the research, emphasize that there are no specific answers to the questions, and inform participants of their opportunity to review interview transcripts before data will be used.

### **Interview One Questions:** \*

- 1) Participants will be asked to share a little bit about themselves as an introduction. If any background information is known, it may be used to begin conversation (i.e. How long have you lived in Saskatoon?)
- 2) Can you tell me about your diagnosis and how you found out that you were ill? How did you make sense of your diagnosis?
- 3) Can you tell me what the experience of being ill has been like for you? For your family members?
- 4) Did you feel like there was sufficient support available to you when you were diagnosed? What about now? Are there any support needs for you or your family that have gone unfulfilled?
- 5) What areas of your life have been most affected by your illness? How has your daily routine changed, if at all, as a result? (Everyday activities, what is taken for granted)
- 6) How has being ill affected your past roles and responsibilities? Are there certain things that you can no longer do? Are there roles that you are unsure if you can fulfill? (i.e. parent, student, employee, wife/husband, etc.)
- 7) How has the illness experience affected your relationship with your body?
- 8) How do you view yourself with respect to other young adults? (the same, different?)
- 9) Do you find that anything in your family life has changed since your diagnosis? Can you describe these changes?
- 10) Do you think that you view your family relationships differently than before the illness experience?
- 11) How do you make sense of being ill? How do you give meaning to your experiences?

### **Interview Two Questions:** \*\*

- 1) Can you tell me about the photographs that you have taken? What do they represent in relation to your experience of illness?
- 2) How did you find the experience of taking photographs? Was this activity helpful in your own thinking about your illness?
- 3) Can you think of any other important aspects of your experience that have not been discussed yet? Is there something specific that you want other people to know about your experience?

\*If participants chose to complete one longer interview, both Interview One and Interview Two questions were drawn upon.

\*\*Interview Two also included follow-up questions emerging from the initial interviews that were specific to each participant.