

**SELF-DISCLOSURE, SELF-IDENTITY AND ILLNESS CENTRALITY AFTER  
CANCER: THE EXPERIENCES OF YOUNG ADULT CANCER SURVIVORS**

by

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A Dissertation Submitted in Partial Fulfillment  
of the Requirements for the Degree of

**Doctor of Philosophy**

in the Graduate Academic Unit of Interdisciplinary Studies

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This thesis, dissertation or report is accepted by the  
Dean of Graduate Studies

THE UNIVERSITY OF NEW BRUNSWICK

May 2017

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## **ABSTRACT**

Cancer can have a profound effect on the well-being of individuals at any age; however, young adults often face additional challenges due to the disruption of many normative developmental tasks associated with this stage in life. One of the most significant tasks associated with young adulthood is the establishment of meaningful relationships. However, many young cancer survivors experience social isolation after treatment and find it difficult to relate to their peers who have forged ahead on the road to independence, careers and families. Self-disclosure, the expression of personal details about oneself, is an essential component of interpersonal relationships and is often viewed as a necessary prerequisite for social support and preventing social isolation. For young adult cancer survivors, disclosing details about their cancer history can be particularly challenging at a crucial developmental stage in life when both personal and professional relationships are just being established. This study provides an in-depth look at the experiences of young adult cancer survivors, their motivations for self-disclosure, and the sense of identity that develops as they attempt to reintegrate back into the social world after the completion of cancer treatment. Using a constructivist grounded theory approach, 28 telephone interviews were conducted with young adults from across Canada diagnosed between the ages of 18-39 with the two most common types of cancer in young men (testicular) and women (breast).

This dissertation is presented in three manuscripts. The first manuscript is based on the study methodology and highlights the challenges and opportunities for incorporating reflexivity throughout the research process. The second manuscript focuses on the motivations for cancer history disclosure described by the young survivors in this study

and some of the situational/contextual factors influencing their disclosure decisions. The third manuscript highlights some of the ways in which young adult cancer survivors (re)construct, redefine, and/or embrace their identities post-cancer and how they situate their cancer experience within their overall self-concept. This dissertation will be useful in the development of support programs and informational resources related to communication and interpersonal relationships after cancer that are tailored to the unique needs of young adult cancer survivors.

## **DEDICATION**

In loving memory of my beautiful mother, Shirley-Dale Easley (b. Feb. 1942 – d. Feb. 2012), who instilled in me a love of learning and taught me to believe that anything is possible. She is the one who showed me the meaning of true determination and resilience in the face of adversity, and the importance of seizing every opportunity to live life to the fullest. If you ever want to know the true meaning of life, spend time with someone who is fighting for every scrap of it. I feel blessed to have been along for the ride. This is for you Li'l Buddy.

## ACKNOWLEDGEMENTS

There are hardly enough words to express my gratitude to all of the people in my life who have helped me through this endeavor. First, I'd like to thank my supervisor, Dr. Baukje (Bo) Miedema, for her continued support, encouragement, patience and for all of the work opportunities over the years. I'd also like to give a big thank-you to Dr. Roanne Thomas for the moral support, opportunities and mentoring throughout my studies. Many thanks to my co-supervisor Dr. Nicole Letourneau and committee member Dr. Lynne Robinson for their support along the way. And a special thank you to all of the wonderful participants who shared their stories with me.

There are far too many friends and family members to thank individually, but I'd like to highlight a few that have helped me make it to this point. To my wonderfully wild, loving and inspiring family whom I love dearly: I could not have ever made it through the last few years without your support, encouragement and laughter. To my girls, Caroline Brennan, Lisa Lewis, Bessie McAvity, Stacey MacLean, Dominique Gillis and Sylvia Reentovich: thank you for standing by my side through all of my triumphs and tragedies. I couldn't be better equipped to take on the world than I am with you all in my corner. To Dominic and Darren O'Donnell: thank you for being the bright lights through one of my darkest times when Mom died. I will be forever grateful. A huge thank you goes to Yvonne Anisimowicz for the moral support, ramen dates and editing wizardry. To my godmother Anne Mitton: thank you for honouring Mom and "acting accordingly". And finally, to my dear brothers Rob and Tom Easley: you are two of the best humans I know and I couldn't feel more blessed to have you both as brothers. To all of you: may you never have to hear me utter the words "I have to work on my thesis" ever again.

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## **CHAPTER I**

### **General Introduction**

Approximately 7,600 young adults aged 15-39 are diagnosed with cancer each year in Canada (Canadian Partnership Against Cancer [CPAC], 2017). The overall impact of cancer and its treatment can be difficult for all survivors; however, young adult survivors often face additional challenges in terms of work, education, relationships, sexuality, and financial issues at a stage in their lives when their peers are forging ahead on the road to independence, careers, and families (Bleyer & Barr, 2009; D'Agostino, Penney, & Zebrack, 2011; Miedema, Easley, & Hamilton 2006; Wilkins, D'Agostino, Penney, Barr, & Nathan, 2014). Young adulthood is often characterized as a time of transition when many individuals struggle to find emotional and financial independence and may still be in search of secure relationships and stable employment (Miedema et al., 2006). For young adults diagnosed with cancer, these challenges become greater as they come to terms with the physical, psychological and social impact of cancer and cancer treatments. Because of their early stage in life, young adults surviving a cancer diagnosis potentially face a long life of dealing with these effects of cancer (National Cancer Institute, 2002).

Social support and social reintegration are integral parts of promoting resilience following cancer, particularly for younger populations (Rowland & Baker, 2005). Systemic issues such as difficulty entering the workforce, access to supplemental health insurance and financial assistance as well as personal issues such as difficulty relating to others after cancer may be barriers to social reintegration following treatment. An important issue for young adults faced with the many personal and professional

challenges after cancer treatment is the decision of if, when, to whom or how to share information about cancer with their family, peers, co-workers, new acquaintances, or potential intimate partners (Hamilton & Zebrack, 2011; Thaler-DeMers, 2001; Zebrack, Chesler, & Penn, 2007). Young adult cancer survivors often have to navigate their way between the desire to disclose information about themselves as a means of developing and strengthening relationships with others, and the desire to withhold personal details about themselves in an effort to maintain privacy. The decision to disclose personal details to others involves an intricate negotiation process as individuals weigh both the potential risks and benefits of disclosure (Berg & Derlega, 1987; Chaudoir & Fisher, 2010; Greene, 2009; Omarzu, 2000; Barnett, Shuk, Conway, & Ford, 2014). For young adults diagnosed with cancer, self-disclosure may be particularly challenging at a crucial developmental stage in life when both personal and professional relationships are being established.

The goal of this study was to explore the disclosure patterns of young adult cancer survivors and to examine the impact these disclosure decisions have had on their social interactions and environments, both personally and professionally. In this dissertation, I focus specifically on the motivations and situational/contextual factors contributing to cancer history disclosure decisions as described by the young adult cancer survivors who participated in this study. Using a qualitative, constructivist grounded theory approach, I interviewed 28 young adult cancer survivors (16 breast cancer; 12 testicular cancer) who were diagnosed between the ages of 18 and 39 and who were at least 1 year post-diagnosis. I wanted to capture the experiences of young cancer survivors at various stages of their survivorship years in order to better understand their disclosure decisions after

the completion of cancer treatment as they attempt to socially reintegrate back into their pre-cancer worlds. In this context, I define social reintegration as the process of integrating back into mainstream society, and thus to benefit from the opportunities and services available to the members of the general public. Documenting the ways in which young adults cope with and communicate about their cancer experiences after treatment offers valuable insight into how they identify themselves post-treatment, how they conceptualize their own social support networks and how they relate to those around them. This information will be beneficial to young cancer survivors as they transition from patient to survivor and attempt to (re)integrate into the social world, both personally and professionally. It will also be useful in the development of support programs and informational resources related to communication and interpersonal relationships after cancer that are tailored to the unique needs of young adult cancer survivors.

## **Background and Significance**

### **Cancer in Young Adults**

Age can play a major role in life orientation and in the adaptation to immediate and long-term stressors such as the effects of cancer; however, little is known about the survivorship issues and support needs after cancer for younger populations (Johansen, 2007; Warner et al., 2016; Zebrack, 2008). Because the number of young adults diagnosed with cancer is small relative to older adults, and parents are no longer their primary advocates as in childhood cancer, their unique needs often get overlooked. While a considerable body of literature exists for young adult survivors of childhood cancer and survivors of adult cancer, relatively little is still known about the health and supportive care needs of individuals diagnosed in the late adolescent and young adult years (Barnett

et al., 2016; Barr, 2011; Bleyer & Barr, 2009; Soliman & Agresta, 2008; Warner et al., 2016; Zebrack, Mills, & Weitzman, 2007). Although childhood cancer survivors face many of the same issues as young adult survivors, there are still a number of unique challenges related to being diagnosed at a time of life that is characterized as the starting point of working life, family life and the quest for emotional and financial independence (Barnett et al., 2016; D'Agostino et al., 2011; Miedema, Hamilton, & Easley, 2007; Warner et al., 2016; Zebrack, 2008).

From a developmental perspective, young adults with cancer are at a life stage when a serious illness is not anticipated and the stress of cancer is concurrent with the many other life stresses associated with this stage of life (Barnett et al., 2016; Wilkins, 2014; Woodgate, 2006). Specific issues for younger cancer survivors include survival concerns for those who have young children; dating and relationship issues; concerns about the loss of fertility due to premature menopause and early ovarian decline (for women) and sterility (for men); body image and sexuality issues due to surgical alterations of the body and hormonal changes as a result of treatment; and concerns about career and work (Avis, Crawford, & Manual, 2005; Aziz, 2007; Barnett et al., 2016; Ganz, Greendale, Peterson, Kahn, & Bower, 2003; Hamilton & Zebrack, 2011; Ramphal et al., 2016; Tindle, Denver, & Lilley, 2009; Zebrack, 2008).

Breast cancer is the most common type of cancer and the most common cause of death among young women. According to the Canadian Cancer Society's Advisory Committee on Cancer Statistics, it is estimated that 17% of all new diagnoses of breast cancer are among women under the age of 50. Survival has been improving gradually in the past decade, and the 5-year survival rate for breast cancer in Canada (excluding

Quebec) is now 85% for this age group (CCSACCS, 2016). Interest in the experience of cancer survivorship and the rehabilitation needs of young women with breast cancer is heightened by the growing number of studies showing that younger women have a greater physical, psychological, and social morbidity and poorer quality of life after a breast cancer diagnosis than older women (Avis et al., 2005; Aziz, 2007; Ganz et al., 2003; Kornblith et al., 2007; Kroenke et al., 2004; Ronson & Body, 2002). Breast cancer occurring in young women tends to be more biologically aggressive with higher rates of recurrence than older women (Shannon & Smith, 2003). Due to the tendency for breast cancer in young women to be diagnosed at a more advanced stage, it is likely that younger patients will require more aggressive treatments and will require adjuvant treatment such as chemotherapy and hormonal therapy (Miedema & Easley, 2012). Furthermore, it has been reported that patients who receive more doses of chemotherapy report slower improvement in quality of life after initial diagnosis and surgery (Bleyer & Barr, 2009). Breast cancer can also have a negative impact on body image, particularly in younger women (Paterson, Lengacher, Donovan, Kip, & Tofthagen, 2016). In Western culture, breasts are seen as symbols of womanhood and sexuality. As such, cancer in the breasts can have a huge impact on women's sense of femininity and self-identity, often leading to problems with intimacy and sexuality (Bleyer & Barr, 2009; Ganz et al., 2003; Paterson et al., 2016).

Much like the impact of breast cancer on femininity, testicular cancer affects men in an area where notions of masculinity and virility intersect (Gurevich, Bishop, Bower, Malka, & Nyhof-Young, 2004). Sexual dysfunction, body image issues, self-esteem, and self-identity are all issues relevant to this type of cancer (Hayes-Lattin & Nichols, 2009).

Testicular cancer is the most common malignancy in young men between the ages of 20 and 44 in Canada (Cancer Care Ontario [CCO], 2006). Although the incidence rate for this type of cancer is on the rise in this age group, improvements in treatment options over the past decade have greatly improved the five-year survival rate which is now over 96% (CCO, 2006; CCSACCS, 2016; Hayes-Lattin & Nichols, 2009). Treatment for testicular cancer typically involves some combination of surgery, chemotherapy, and radiation. Because of the young age at diagnosis and the high survival rates following testicular cancer treatment, survivorship issues become tremendously important. While mortality may no longer pose the risk it did in the past, other important physical and psychosocial outcomes must be considered, such as fertility and sexuality issues, body image, physical functioning, latent cardiovascular and neurological toxicities, fatigue, and overall quality of life issues (Hayes-Lattin & Nichols, 2009). However, compared to breast cancer, there is a paucity of information pertaining to the experiences of young men with testicular cancer and its treatment.

### **Impact of Cancer**

Although cancer treatments are beneficial and lifesaving, they are also associated with many physical, psychological and social residual effects which may have an impact on the quality of life of people surviving cancer (Miedema & Easley, 2012). Adjustment to the diagnosis and treatment of cancer is a complex process that does not necessarily end at the completion of active treatment. Adverse treatment-related issues can unfold over a long period of time and carry with them the potential to contribute to the ongoing burden of illness, health care costs, and decreased length and quality of survival (Aziz, 2007). Potential long-term physical effects of cancer can include cardiac dysfunction,



fatigue, lung capacity depletion, pain, lymphedema, secondary cancers, fertility problems, and sexual impairment. Potential psychological late-effects include body image issues, fear and anxiety about recurrence, depression, and feelings of uncertainty and social isolation. Social effects may include changes in interpersonal relationships, concerns regarding finances and health insurance, and difficulty returning to work or seeking employment due to impairment (Barnett et al., 2016; Hewitt, Greenfield, & Stovall, 2006; Ramphal et al., 2016). Although most of these physical and psychosocial long-term effects are associated with the diagnosis and treatment of cancer regardless of age, young adults with cancer potentially face a long life of dealing with these issues due to having the disease at an early stage in life (Miedema et al 2007; Zebrack, 2008).

Studies show that many young adult cancer survivors experience impaired achievement in education, employment, and social goals when compared to their peers (Brown & Tai-Seale, 1992; Langveld et al., 2003; Stern, Norman, & Zevon, 1991; Zebrack, Chesler, & Penn, 2007). Young adults may also be particularly vulnerable to difficulties with work after cancer, as many are only in the early stages of career development and may not have stable employment or a permanent position in the workforce. According to the International Labour Organization (2006), youth in general (in industrialized and developed economies) are 2.3 times more likely to be unemployed as compared to adult populations. They are also more likely to have temporary, part-time or casual work and insecure arrangements with limited labour protection (International Labour Organization, 2006). A cancer history may impact the marketability of an individual in the workforce, due to physical limitations, absenteeism from work due to medical appointments, potential for long-term disability down the road, health insurance

needs, cognitive impairments, or an overall stigma or attitude towards work ability after cancer. According to a survey of 200 work supervisors, almost half of them admitted that a cancer history would affect their hiring decision of a qualified applicant (Hoffman, 2005). The stigmatization of cancer can impact how the survivor is perceived as an employee and co-worker. Co-workers and managers may see someone with a cancer history as being incapable of performing tasks, they may fear that the cancer is contagious, and employers may see them as poor candidates for promotion, even if the survivor is without any ongoing disability (Brown & Tai-Seale, 1992; Holland & Reznik, 2005; Short & Vargo, 2006). Many social connections and networks are created and maintained through interactions in the workplace, and losing these ties may have a great impact on an individual's concept of self in relation to others and the sense of belonging (Maunsell, Brisson, Dubois, Lauzier, & Fraser, 1999; Morrison & Thomas, 2015; Steiner, Cavender, Main, & Bradley, 2004).

According to Bleyer and Barr (2009) young adults are often more prone than older adults to long-lasting adverse cognitive and psychological effects, poorer mental health, more depression, reduced vitality and less satisfaction with life after cancer. In one study of young breast cancer survivors, the decline in the overall health-related quality of life was twice that reported by older women (Kroenke et al., 2004). Research suggests that 15-30% of childhood and young adult cancer survivors are significantly more likely to show signs of psychological distress than comparison groups (Hobbie et al., 2000; Richardson, Baron Nelson, & Meeske, 1999; Zeltzer et al., 1997). In a study on young adult survivors of childhood cancer, 10-30% of the participants met most or all of the criteria for Post-traumatic Stress Disorder, and an additional proportion met the

criteria for at least one trauma symptom (Erickson & Steiner, 2001). However, not all experiences after cancer are negative. Several researchers have demonstrated that many young adult cancer survivors show no signs of significant distress and in some instances, psychological and quality of life outcomes are the same or even better than those among comparison populations (Gray et al., 1992; Grinyer, 2009; Maggiolini et al., 2000; Norum & Wist, 1996). New paradigms of trauma raise the possibility that many individuals experience *posttraumatic growth* after cancer and actually have an improved quality of life (Folkman & Greer, 2000; Zebrack, Chesler, & Penn, 2007; Zebrack et al., 2015). In summary, cancer and treatments for cancer can have many physical and psychosocial side effects; however, the impact of these effects on the individual with cancer can vary greatly depending on a multitude of factors such as personal characteristics, disease type, treatment type, social environments, and overall social support (Zebrack et al., 2007; Wilkins et al., 2014).

The impact of cancer on social interactions and interpersonal communication is of particular interest in younger populations as young adults navigate their way down the road towards adulthood. Young adults with cancer commonly experience changes in friendships and a sense of isolation from friends due to lengthy time away from home, school, or work, and the feeling that they no longer can relate to their peers (Adams, 2003; Zebrack, 2008). Dating and marital relationships can be challenging after cancer as survivors deal with the physical and psychological effects of treatment, the difficulties relating to others, or the overall fear of stigmatization or rejection (Hewitt et al., 2006; Hamilton & Zebrack, 2011). Because young adults are less likely to be in long-term, stable relationships compared to older adults, they may be particularly at risk for

difficulties with intimate relationships and dating (Robinson, Miedema, & Easley, 2014). Treatment for breast and testicular cancer often involves surgery, radiation, and chemotherapy which can cause sexual impairment, decreased sexual desire, premature menopause and sterility, which can affect overall notions of masculinity and femininity (Brodsky, 1995; Nancarrow Clarke, 2004; Tindle, Denver, & Lilley, 2009).

### **Self-disclosure in the Context of Cancer**

Self-disclosure is a term that refers to the expression of personal information about oneself to others (Yoo, Aviv, Levine, Ewing, & Au, 2009). It is an integral part of relationship development and maintenance, and is essential to the ways in which we communicate to others about who we are, what we feel, what we have experienced and what is important to us (Yep, 2000). An overall sense of support induced through self-disclosure and social inclusion has been found to enhance the psychological well-being and coping abilities of those faced with an illness or disability (Figueiredo, Fries, & Ingram, 2004; Munir, Leka, & Griffiths, 2005). However, the disclosure decision is rarely a simple process and often has great social implications (Berg & Derlega, 1987; Omarzu, 2000; Henderson, Davison, Pennebaker, Gatchel, & Baum, 2002). Individuals may experience benefits from self-disclosure as an expression of a new sense of self-identity, as a means of strengthening existing relationships and developing new ones, or as an overall coping mechanism to come to terms with a catastrophic life event (Knapp & Vangelisti, 1999; Munir et al., 2005). On the other hand, potential risks may include the fear of stigmatization, a fear of negative reactions or unsupportive behaviour, or even the fear of losing an opportunity for employment or friendship (Figueiredo et al., 2004).

Although there is growing body of literature on self-disclosure in general, very few studies have focused on disclosure topics within the context of cancer (Gray, Fitch, Phillips, Labreacque, & Fergus, 2000). Yoo and colleagues (2009) conducted a study on the impact of self-disclosure on women with breast cancer. In this study, they found that self-disclosure for these women involved a high level of *emotion work*, a type of work to elicit feelings in others and maintain one's own social roles by adhering to emotional norms and expectations. The fear of burdening family and friends with their illness was a major concern for this group of women, which limited their social support networks and impacted their emotional well-being (Yoo et al., 2009). In another study of women with breast cancer, Henderson and colleagues (2002) found that willingness to disclose appeared to be based on individual attitudes about disclosure. They found that most participants had no difficulties disclosing details about their illness and most chose to disclose because of the opportunities for support that they anticipated from sharing with others (Henderson et al., 2002). Figueiredo and colleagues (2004) found similar results in their survey of disclosure patterns of breast cancer patients and unsupportive social interactions. In this study, the researchers focused specifically on the disclosure of thoughts and feelings to others rather than on disclosing information about their cancer diagnosis and history. In this context, unsupportive reactions to the disclosure of feelings were significantly associated with social role limitations due to emotional problems and decreased social functioning (Figueiredo et al., 2004).

Research shows that women tend to be more open about self-disclosing personal details about an illness or about their feelings and emotions in general as compared to their male counterparts (Barak & Gluck-Ofri, 2007; Consedine, Sabag-Cohen, &

Kirvoshekova, 2007; Kameny & Bearison, 2002; Yoo et al., 2009). In a qualitative study of disclosure patterns among men with prostate cancer, Gray and colleagues (2000) found that most men avoided disclosure about their illness entirely, except when absolutely necessary. Factors that limited self-disclosure for these participants included a fear of stigmatization and a low perceived need of support as well as the fear of burdening others (Gray et al. 2000).

According to Charmaz (1991), reluctance to disclose information to others about an illness revolves around the need to maintain control over one's identity. She discusses two types of disclosure: one that is protective and one that is spontaneous. Spontaneous disclosure involves freely expressing oneself without trying to control what is said, whereas protective disclosure involves more conscious thought and emotional calculations, providing information without disclosing associated emotions, thereby reducing vulnerability and perceived threats of disclosure (Charmaz, 1991). Robinson, Kocum, Loughlin, Bryson, and Dimoff (2015) found similar results in their study of the experiences of breast cancer survivors returning to work after cancer. They found that a sense of personal control was a strong motivating factor contributing to disclosure decisions for these women at work; however, there were a number of challenges to confront in this quest to maintain control. Participants in their study often felt that they were forced to disclose details of their cancer due to the visibility of the after-effects from treatment and physical limitations; many also faced the challenge of having others disclosing details about their cancer; and most found it challenging to deal with the many emotions of disclosing their cancer history in the workplace (Robinson et al., 2015).

Focusing specifically on disclosure decisions among young adult cancer survivors, Hilton, Emslie, Hunt, Chapple, and Zeibland (2009) conducted a secondary analysis of interviews with young adults between the ages of 18 and 34 diagnosed with cancer. They found that most participants were open about disclosing their cancer diagnosis with their family and friends; however, the young men in the study were more likely to be more secretive about their disclosure than the young women (Hilton et al., 2009). Barnett and colleagues (2014) used a qualitative approach to examine cancer-related disclosure among survivors who were diagnosed between the ages of 14 and 21 years old. They identified three major themes: the complex process involved in the decision to tell (“it depends” decision-making process); the perception of others’ responses; and the method of disclosure (verbal, written and behavioural). These processes and themes identified demonstrate the importance of peer relationships, possible interactions and reactions, and the contextual factors (relationship potential, means of disclosure) that may impact cancer-related disclosure (Barnett et al 2014).

### **Gaps in Prior Knowledge**

Most of what is known about the experiences of young adult cancer survivors is based on research of young adult survivors of pediatric cancers (Warner et al., 2016). Given the identified need for more research on issues pertaining specifically to those diagnosed in the young adult years, as well as the lack of information and research on self-disclosure within the context of cancer, this study will fill a significant gap in research and practical knowledge surrounding survivorship issues and interpersonal relationships among this population. Most research that has been done on the topic of self-disclosure and in the area of young adult cancer has been from a quantitative

perspective. The purpose of this research is to qualitatively explore and document how young adults communicate about their cancer experience and how their disclosure decisions have impacted their pathways to social reintegration, both personally and professionally. Disclosure decisions are particularly important to assess in young adults due to their early stage of career and long-term relationship development. Learning more about the experiences of young adults after cancer, particularly their communication issues and social support needs, will help the continued development of age-appropriate resources, psychosocial interventions, and educational programs that support young adults in the development and maintenance of social relationships after cancer.

## **Research Design and Methodology**

### **Study Design**

In order to research the disclosure patterns of young breast and testicular cancer survivors, I used a qualitative, grounded theory approach involving semi-structured interviews. Grounded theory is a useful methodology for studies aimed at discovering the processes and patterns underlying human interaction to help better understand how a group of people define their reality through their social interactions (Cutcliffe, 2000; Lawrence & Tar, 2013). Specifically, I have chosen to use constructivist grounded theory (CGT) as a guiding methodology that emphasizes the interactive relationship between the researcher and the participants in the research process (Charmaz, 2000). This research paradigm focuses on the co-construction of meaning and brings the centrality of the researcher as author to the methodological forefront (Charmaz, 2000; Mills, Bonner, & Francis, 2006). A CGT approach adopts the tools of grounded theory but assumes the position that the world consists of multiple realities and thereby does not support the



objectivist and positivist assumptions of the classic method presented by Glaser and Strauss (Charmaz, 2000; Charmaz 2006; Kenny & Fourie, 2015; Mills et al., 2006). The result is that a constructivist approach offers an interpretive portrayal of a reality rather than an exact picture of it (Charmaz 2000, 2006). In other words, the theory resulting from the interpretation of the data emphasizes understanding rather than explanation. Further details of this methodology are presented in Chapter 2.

### **Study Population**

There is substantial variability in the age ranges used to define young adulthood. Definitions can vary based on clinical classifications and biological characteristics of the cancers typical of early adulthood; psychosocial and developmental factors; or whether or not adolescents are included in the age range (Bleyer & Barr, 2009; Miedema et al, 2007; Zebrack, 2008). For the purpose of this study, I have chosen to use the age range of 18-39 years as this is a timeframe when many young adults are still searching for emotional and financial independence and when most long-term personal and professional relationships and goals are in the developmental stage (Miedema et al., 2007). In the system performance report released by the Canadian Partnership Against Cancer, the upper age limit used to define young adulthood is 39, and the age 18 marks the transition from adolescence to young adulthood (CPAC, 2017). I also chose ages 18-39 in order to align with the age range used by the national non-profit organization Young Adult Cancer Canada for their support programming. Although there may be great variability between the life-stages of an 18-year-old and a 39-year-old, I felt that inclusion of all young adults within this age range would contribute to the overall knowledge of the experiences of women and men dealing with cancer throughout the wide span of the young adult years.

I focused the research on the experiences of young women diagnosed with breast cancer and young men diagnosed with testicular cancer because these two types of cancer have the highest incidence rates among young adults and are both similar in that they are highly associated with sexuality and gender identity issues (masculinity/femininity) (CCO, 2006; Bleyer & Barr, 2009).

### **Inclusion Criteria**

To be eligible to participate in this study, potential participants had to be diagnosed with breast or testicular cancer between the ages of 18 and 39 years; able to consent; able to speak either English or French; and had to be at least 1 year post-diagnosis of cancer. There was no upper limit to the number of years since diagnosis in order to allow the inclusion of young adults at various stages of the cancer journey, who were either ready to embark or were already into the survivorship phase of the illness experience.

### **Recruitment**

Participants were recruited using a variety of methods. Recruitment information was sent to contacts at all young adult, testicular, and breast cancer specific organizations and support groups in each province and territory (where applicable); electronic recruitment information was sent out via e-newsletters (e.g., Young Adult Cancer Canada), online advertising and message boards (e.g., Kijiji), public forums, and through the social networking sites Facebook and Twitter. Interested participants were able to contact me via e-mail, Facebook, Twitter, or a toll-free telephone number. In order to ensure a diverse sample of participants and experiences, I then theoretically sampled to

help refine emerging categories based on cancer type, province, and geographical location (urban/rural).

### **Data Collection**

Data for this study were collected via semi-structured telephone interviews. Although critics of telephone interviewing techniques claim that important non-verbal cues may be missed, other researchers indicate that the benefits of telephone interviews outweigh the challenges and they found little difference in the quality of data collected compared to face-to-face interviews (Musselwhite, Cuff, McGregor, & King, 2007; Sturges & Hanrahan, 2004; Wilson, Roe, & Wright, 1998). By conducting interviews over the telephone, I was able to save on travel costs and was able to include participants from across Canada. Because of the nature of the research topic of self-disclosure and potentially sensitive topics discussed such as sexuality, fertility, and interpersonal relationships, the increased anonymity associated with telephone interviews may have enabled and encouraged participants to be more forthcoming. My expectation was that this method of data collection would also increase the comfort level of male participants being interviewed by a female researcher.

### **Ethics**

The research protocol for this study was reviewed by the University of New Brunswick Research Ethics Board (#2010-085) and the Horizon Health Network Research Ethics Board (#2010-1503). After initial contact, potential participants were screened for eligibility and those that fit the inclusion criteria and agreed to participate were mailed, faxed, or e-mailed a copy of the consent form (see Appendix A) for review.

Prior to the telephone interview, the consent form was discussed with the participant, any questions were answered, and oral consent was obtained.

### **Interview Questions**

A semi-structured interview guide was used with questions designed to encourage participants to discuss their feelings and experiences in depth (see Appendix B). The interview began with open-ended questions asking participants to describe their cancer experiences starting with the time leading up to the diagnosis through to where they were in their cancer journey at the time of interview. Probes were added to encourage participants to discuss any physical, psychological, and social issues experienced (e.g., sexuality, career, education, fertility, body image, financial). The second section of the interview included questions specifically about relationships, self-disclosure patterns, and motivations. The third section involved more existential questions about the impact and meaning of cancer in their lives and whether having cancer had changed them in any way. The interview concluded with a question related to the experiences and any unique challenges of having cancer as a young adult. After the interview, socio-demographic information was collected via questionnaire (see Appendix C) to create a participant profile (see Appendix D). I felt it was important to examine self-disclosure both within the context of personal as well as professional relationships in order to document any differences that may exist between the private and public lives of individuals. In a personal context, disclosure decisions may impact other people (e.g., potential partners and fertility/sexuality issues) or may be influenced by the visibility of scars, the desire for closeness and understanding, or as a form of reciprocal disclosure interaction as a means of relating to others. However, in the professional setting, it may not be a necessity to

disclose a cancer history as it may not be directly relevant in the workplace or to professional relationships with colleagues.

## **Analysis**

Interviews were digitally recorded, transcribed verbatim, and then checked for accuracy. The transcripts were entered into a qualitative data analysis software program NVivo 9 (QSR International, 2010) designed to help facilitate data management and coding. CGT methodology follows similar procedures as traditional grounded theory approaches (constant comparison, memoing, theoretical sampling and saturation); however, the coding procedure is more interpretive in nature with a stronger emphasis on the meanings that participants attribute to their experiences (Charmaz, 2006; Kenny & Fourie, 2015). CGT involves a two-tier coding procedure. The first step was *initial (open) coding* in which the data were coded line-by-line to look for overarching themes and theoretical cues (Kenny & Fourie, 2015). The next step was *refocused coding*, where significant and recurring themes were identified, sorted, synthesized and compared with the rest of the data. Memoing was used to keep track of ideas that developed when comparing concepts to concepts in the evolving theory; and theoretical sampling helped to ensure a diverse sample of participants (Creswell, 1998). Following the CGT approach, data analysis started immediately after the first telephone interview and continued concurrently with the rest of the data collection. The purpose of using this technique was to allow emerging data to be coded as it was collected, which helped to shape the direction the research took from that point on (Creswell, 1998). This approach was not linear but concurrent, with data collection, analysis, and theorizing occurring at the same time using a *constant comparison* method from the outset of the research

process (Creswell, 1998; McGhee, Marland, & Atkinson, 2007). A CGT approach allows the researcher to be actively involved in the data collection process while interacting with participants, asking questions and inviting clarification or elaboration on different aspects of the communication as the interview progresses (Hall & Callery, 2001).

### **Data Trustworthiness**

Since issues concerning reliability and validity are less defined and are often difficult to measure in qualitative research, the term *trustworthiness* is often applied when referring to the rigour of a qualitative study (Creswell, 1998). The following steps were taken to ensure the overall rigour of this research process: a literature review; memoing and reflective note taking throughout the entire research process; a detailed trail of methodological decisions (*audit trail*); systematic data coding and analysis; and use of direct quotes so that the perspectives of the participants are represented as clearly as possible. A summary of the findings was shared with participants for comment and review as a form of *member checking* to help decrease the possibility of any inaccurate portrayals of their experiences. Only positive feedback was received from those that responded.

### **Thesis Outline**

For this dissertation, I chose to organize and present the findings in an article-based format which differs from a traditional thesis in that the chapters are written as stand-alone manuscripts targeted to specific journals for publication. The dissertation consists of five chapters: an introductory chapter, a methods chapter, two chapters featuring the findings of the study, and a final chapter which synthesizes the entire work. The following is a brief description of each chapter:

- Chapter 1 provides an introduction to the research topic, a review of the literature, a description of the study design, and the thesis outline.
- Chapter 2 focuses on the methodology of the study and features the first manuscript entitled “Situating the self in research: Integrating researcher perspective and place throughout the research process.” In this article, I discuss my dual role as both a researcher and a young adult cancer survivor, researching young adult cancer survivors. The manuscript highlights the methodological choices I made for this study, as well as the challenges and opportunities that emerged as I attempted to situate myself and my perspective throughout the research process.
- Chapter 3 presents the main findings of the study and features the manuscript entitled “Motivations for cancer history disclosure among young adult cancer survivors.” This article focuses on the specific motivations and the situational/contextual factors which influence self-disclosure decisions among young adult cancer survivors.
- Chapter 4 features the manuscript entitled “Self-identity and illness centrality after cancer: The experiences of young adult cancer survivors,” which is based on the prominent theme that emerged from the study while exploring cancer history disclosure decisions among young adults.
- Chapter 5 is the discussion and conclusion of the dissertation which provides an overall synthesis of the data presented in previous chapters, study limitations, and suggested future research.

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## CHAPTER II

### **Manuscript 1: Situating the Self in Research: Integrating Researcher Perspective and Place throughout the Research Process**

#### **Relationship of Manuscript 1 to the Dissertation**

This chapter is based on the methodology of my research study, specifically the ways in which I situated myself as a young adult cancer survivor researching young adult cancer survivors. It includes suggestions for incorporating reflexivity into the research process and concludes by stressing the importance for researchers to be mindful of their position and influence on the research outcomes.

Parts of this manuscript were presented as the keynote address at the Innovations in Qualitative Research Conference held at the University of Saskatchewan on June 11-13, 2012. The manuscript will be revised to meet the author guidelines for submission to the journal *Qualitative Health Research*. The manuscript is written in a commentary style similar to other manuscripts in the journal and as outlined in the author guidelines.

## Introduction

The question of objectivity in research has long been a debate among scholars. Quantitative researchers often stress the importance of taking a neutral, unbiased stance in the research process as a means of helping to ensure that the study is valid, reliable and replicable (Denzin & Lincoln, 2000). However, qualitative researchers argue that there is no such thing as bias-free research and that the influence of the researcher should be recognized as an explicit part of the knowledge created (Denzin & Lincoln, 2000; Finlay, 2002a; Ratner, 2002). From this qualitative stance, recognizing the influence of researcher subjectivity throughout the research process is an acknowledgement that how knowledge is acquired and interpreted is equally as important as what the claims are being made (Altheide & Johnson, 1994; Mauthner & Doucet, 2003). Taking a qualitative approach often involves a shift in our understanding of data collection from something objective to recognizing the role of the researcher as the main research instrument and acknowledging that the researcher's background, insights, and experiences can play an integral role in the research process itself (Bourke, 2014; Denzin & Lincoln, 2000). As Finlay (2002a) states, "we no longer seek to eradicate the researcher's presence - instead subjectivity in research is transformed from a problem to an opportunity" (p.212).

Given the inherent subjectivity of an interpretive, qualitative approach, it is essential for researchers to examine where they are in relation to the area of interest in order to make meaningful linkages to the data that is generated and presented. However, situating the self in research is by no means a simple process. Lines between the researcher and the researched often become blurred, especially when there are shared experiences and backgrounds that may intertwine and overlap. This was particularly the

case for me when conducting my research as part of my doctoral program. My doctoral research explores the topic of self-disclosure among young adult cancer survivors and the impact disclosure decisions have on the social interactions of young survivors, both personally and professionally. The study was inspired by my own experiences as a young adult cancer survivor, which raised a whole new level of consideration and personal reflection as I set out to design the study. Am I too close to the research topic? Do I owe it to my participants to disclose my cancer history as I am asking them to disclose and talk about their cancer experience? Is my history and background even relevant? Is it important? Is it necessary to disclose? All of these questions and many more arose as I forged my way down the research path. Learning to question my own research and ask questions of how the data were created was one of the most challenging parts of this process. Added to that was the dilemma of what to do with all these reflexive thoughts and information, let alone how to make sense of them and pull them all together. In this chapter I discuss some of the questions, challenges, and opportunities that emerged throughout my doctoral research experience as I sought ways to professionally situate myself within my research while still representing the voices of the research participants. It is my hope that by sharing my thought process as I developed and conducted my research study that others may benefit and be encouraged to try out similar methods to delve deeper into their research topics and their place within the research.

### **Insider vs. Outsider Perspective**

Anthropologists have long used the terms *emic* and *etic* to refer to the different positions from which to study human behaviour. Emic refers to the insider position and suggests a more subjective standpoint, whereas etic refers to the outsider position that is

more objective and distanced from the research topic (Kanuhaha, 2000). The role of these two different perspectives in research has been the subject of much debate among qualitative researchers. While many acknowledge the importance of situating themselves within the research context, whether it is essential to have intimate knowledge and shared experience with the research participants is often contested (West, Stewart, Foster, & Usher, 2013). Supporters of the emic perspective argue that this insider knowledge helps the researcher establish legitimacy and develop rapport with participants, which may allow them quicker access to the study population and result in richer data collected if they feel they have a shared history or experience (Dwyer & Buckle, 2009; West et al., 2013). Others feel that being too close and too familiar with a topic may cause researchers to overlook important aspects or have difficulty separating their experiences from those of the people they are studying (Dwyer & Buckle, 2009; Oliver, 2010; West et al., 2013). Denzin (1994) refers to this as the *interpretive crisis*, as researchers continue to debate the idea of bias in qualitative research and the lack of agreement on how much researcher influence is acceptable (Denzin 1994; Ortlipp 2008).

As a cancer survivor and a researcher in the area of psychosocial oncology, I have long struggled with my own positioning within my research. On one hand, there is the fear of being too close to the research subject, opening the door to the potential for researcher bias or closing other doors due to assumed understanding based on my own experiences. On the other hand, being that close to the subject allows for an understanding of the issues that others may not have, allowing me to probe deeper into areas which may get overlooked by other non-survivor researchers. There is also the aspect of increased comfort levels for participants who may feel more at ease sharing

their experiences with a fellow cancer survivor, and in this case a fellow young adult cancer survivor. But is there such a thing as being too subjective? How close is too close? Is it necessary for me to disclose my cancer history? What does it add to the research? After careful consideration, I proceeded with my study of the experiences of young adult cancer survivors with all the potential pros and cons of my insider perspective in mind. The next challenge was to figure out exactly how I was going to use my dual role as a researcher and a young adult cancer survivor to get the most out of my research, both academically and personally.

### **Self-Awareness and the Practice of Reflexivity in Research**

The first methodological decision I made was to use a qualitative approach to study self-disclosure. I wanted to get to the heart of what motivates young cancer survivors to disclose (or not) their cancer history, as well as the contextual factors influencing these decisions. Qualitative methods allow the researcher to take a rich, detailed look at why people act the way they do and the feelings they may have about their actions and the world around them (Creswell, 1998; Denzin & Lincoln, 2000). Conducting qualitative interviews requires a great deal of reflection as the researcher attempts to find meaning in the stories and experiences shared by participants. The process of reflection is referred to by qualitative researchers as *reflexivity* and it helps foster an ongoing self-awareness throughout the research process, bringing the role and influence of the researcher to the forefront in the interpretation of the data (Lipp, 2007; Pillow, 2003). I felt that reflexive analysis would be an important element to incorporate into the research design as I learned to recognize how my roles as a researcher and as a cancer survivor converge. Recognizing and being aware of the potential differences and

similarities of my experiences with those of my participants is a helpful way to professionally position myself within the context of the research study (Valandra, 2012). West and colleagues (2013) describe reflexivity as a continual process which can lead to a deeper level of meaning-making and self-awareness as it encourages the researcher to take an inquisitive stance throughout the entire research process. Because of the interpretive nature of qualitative research, being transparent about how the data were interpreted can help augment the credibility and trustworthiness of the research findings (Denzin & Lincoln, 2000; Hall & Callery, 2001; Valandra 2012). In my research, I felt that it was especially important to be reflexive and transparent throughout the research process since I did share a similar background and cancer history with my participants and the line between the researcher and the researched could easily become blurred. As Finlay (2002a) points out, reflexivity can be a helpful way for researchers to “examine the impact of the position, perspective and presence of the researcher” (p. 225).

### **Transparency: Researcher Disclosure**

The second methodological decision I had to make was whether or not I would disclose my cancer history to my participants. It can be challenging as a qualitative researcher to know the boundaries of how much to disclose about oneself to participants, under what pretenses, and for what purpose (Valandra, 2012). Strategic self-disclosure by the interviewer can be a useful way of building rapport with the participant and counteracting any power imbalances that may be present between the interviewer and participant (Abell, Locke, Condor, Gibson, & Stevenson, 2006). I made the decision to disclose my own cancer history to my participants, and to even take it a step beyond by disclosing it openly and proactively on my recruitment materials. Recruitment notices



and advertisements (e.g., social media posts, online forums, cancer support agency websites) included a note to say that I was a researcher and a fellow young adult cancer survivor. Young adult cancer survivors are underrepresented in research, particularly males (Barnett et al., 2016). Because I was researching issues around self-disclosure, it was my hope that someone may feel more comfortable disclosing their cancer history and talking about self-disclosure issues to someone who also had cancer, and therefore be more likely to participate. The specific focus of my study was on breast cancer and testicular cancer survivors, so by disclosing I also hoped that young men would be less hesitant to talk to a young woman about their cancer experiences if they knew that there was a shared experience with cancer. Some researchers have even suggested that interviewer self-disclosure can be a particularly powerful tool when working with adolescents and young adults as it may help empower the participant and allow them to feel more comfortable sharing similar experiences, especially in relation to potentially sensitive topics (Abell et al., 2006; Eder & Fingerson, 2003).

### **Incorporating Reflexivity into the Research Process**

Once I realized the importance of being reflexive throughout the whole research process, I had to determine how to actually be reflexive and figure out what to do with all of my reflections, observations, and insights. I questioned whether these reflective thoughts would be just an act of self-awareness directing the study, or if they were to be shared with the audience in publications and presentations. Do participants need/want to know how you interpreted the data and the personal/professional background from which you came when attempting to interpret the findings? Although there is much discussion in the literature of the importance of reflexivity, the challenges and practicalities of

actually doing it are rarely discussed (Mauthner & Doucet, 2003). It is one thing to acknowledge the importance of reflexivity, and another to actually be reflexive as a researcher. Although it may not be possible to specifically answer all of these questions, they do raise an awareness of both the possibilities and challenges of reflexivity. The following list highlights some of the techniques I used throughout the research process to document and incorporate my reflexive thoughts throughout.

### **Choosing a Research Approach: Constructivist Grounded Theory**

I decided to use a grounded theory approach for my research study. Grounded theorists aim to search for the processes and discover the patterns underlying human interaction in order to understand how a group of people define their reality through their social interactions (Cutcliffe, 2000; Hall & Callery, 2001; Morse & Field, 1995). Specifically, I chose a constructivist grounded theory (CGT) approach, as characterized by Kathy Charmaz (2000), which is based on the epistemological underpinnings of constructivism. Constructivism is a research paradigm that rejects the notion of an objective reality and “assumes the relativism of multiple social realities, recognizes the mutual creation of knowledge by the viewer and the viewed, and aims toward interpretive understanding of subjects’ meanings” (Charmaz, 2000, p. 510). Emphasizing the interactive relationship between the researcher and the participants in the research process, CGT focuses on the co-construction of meaning and brings the centrality of the researcher as author to the methodological forefront (Mills, Bonner, & Francis, 2006a; Charmaz, 2000). A constructivist approach is reflexive in design and helps the researcher to construct and reconstruct meaning from the data which is generated with participants, as opposed to aiming to uncover the objectivist truth as in traditional grounded theory

(Mills, Bonner & Francis, 2006b; Mills, Chapman, Bonner, & Francis, 2007). Critics of CGT warn of researcher bias and claim that the interrelationship between researcher and participant is not a focus in grounded theory and therefore CGT should not be considered grounded theory at all (Glaser, 2002). However, supporters of CGT state that it does not discredit the works of those who take a more objectivist approach. As Bryant (2003) states, CGT merely makes the case for full and proper consideration of issues surrounding the researcher's involvement and role within the study and calls for a cognizance of the potential impact this interactive relationship may have on the resulting theory. For my study, CGT seemed an appropriate methodology to support the inclusion of reflexive practice and helped support my decision to acknowledge my positionality within the research as well as my decision to disclose this positionality openly as part of the research process. Although my goal was to specifically look at the processes and patterns of self-disclosure, my hope was to also discover within this context the meaning that cancer holds for young adults diagnosed with cancer and how that meaning shapes experiences after cancer. A CGT approach enabled me to not only explore the physical, psychological, social, and spiritual journeys of my participants, but also to reflect on my own research journey as I attempted to make meaning out of how these individuals make meaning.

### **Facilitating Reflexivity: Keeping and Using a Research Journal**

One of the methods I used to capture my reflective thoughts and insights was to keep a journal that served as both an outlet for thoughts about the research itself and an outlet for me to document my personal insights, questions, and observations throughout. As LeGallais (2008) states, during the intense part of data collection it is all too easy for

some things to slip by and not get acknowledged, only to then be recognized later in hindsight. By keeping a research journal throughout the whole process, I was able to jot down details and thoughts that required deeper analysis and reflection. Journaling also helped provide a data trail of how the data were interpreted and how research decisions were made, helping to establish rigour throughout the process (Ortlipp 2008).

Documenting these thoughts and insights can be seen as a form of memoing, which is an established part of grounded theory methodology (Creswell, 1998). Both traditional grounded theorists and constructivist grounded theorists use memoing as a reflective tool to record the researcher's thought process around the data (Mills et al., 2006a). Memoing provides the researcher with an opportunity to remember, question, analyze, and make meaning out of the time spent with participants and the data that were generated together (Hall & Callery, 2001; McGhee, 2007).

As an extension of the journaling, I started audio recording my thoughts immediately after the interview by means of what I called my *personal interview*. This became a way to capture the very raw thoughts and questions that came up, both about the research and the impact the interview had on me personally, immediately while they were still fresh in my mind. I would listen to these audio notes before further reflecting on the meaning of these thoughts and questions in my journal. Although this was an extra step that may not have been necessary, it became important to me as a doctoral student as a means of tracking my own growth as a researcher. For the purpose of this study, reflexively documenting my thoughts, feelings, and questions as they arose during the research process helped me be aware of any potential subjective judgements when analyzing a transcript (Valandra, 2012).

## **Analysis of the Interview Style and the Presence of the Researcher Voice**

Another important step in taking a reflexive approach to my research was to take note of the interview style and researcher voice during the data collection phase. For the analysis of the data I used the qualitative data analysis software NVivo 9 (QSR International, 2010) to help categorize and document the themes that emerged from the data. I created a code called *Researcher Voice* where I could document any instance that my voice and/or position was present in the interview. I felt this was an important step for me to keep track of how my shared experience as a cancer survivor may have influenced the participant's expression or opinion. I wanted to be mindful of my closeness as a fellow cancer survivor with shared experiences, while maintaining enough distance as a researcher to be able to confidently interpret the findings as those emerging from the participants and not from me.

As much as it is a co-construction of meaning, the presence of the researcher in the research process can influence the direction the research takes. Because grounded theory methods allow the emerging data to be coded immediately after it is collected, I was able to analyze my own interview style and be mindful of any time my voice may have had an impact on the participants' responses by provoking or inhibiting their responses. For example, early in the data collection I noticed that there were times that the participant would knowingly imply that I understood what they were talking about because of our shared history and fail to go into detail. These moments of shared laughter, unfinished phrases, and familiar references with the participant could possibly go unnoticed without further reflection because they are often so deeply ingrained in the shared experiences (Kanuha, 2000). After analyzing the first few interviews I was able to

recognize this and from that point onward I was mindful to ask the participant to clarify or elaborate on the concept for the record, even if there was an implicit shared understanding.

### **Addressing the Challenges of Reporting Reflexive Data**

After recognizing the importance of reflexivity and finding ways to be reflexive throughout the research process, the next challenge became figuring out what to do with all of this reflexive data. Is it necessary to share these reflective thoughts and ideas with the research participants and the research audience? With presentations and publications that result from research, how and where do you find space to incorporate reflexive notes with restrictions on time and word limits? Research is often presented as a tidy and linear process; however, researchers do not often share the messiness of the research process and the challenges they encounter along the way (Ortlipp, 2008). As Finlay points out,

The nature of positivist hegemony still makes it difficult to publish qualitative research and researchers, with an eye to academic credibility, are often pushed to limit their subjective analysis with all its muddy ambiguity. Even where reflexive exploration is valued, accounts are invariably strangled by constraining word limits set by academic journals. (2002a, p. 227)

Despite the potential constraints when presenting research findings, it is possible to be reflexive and acknowledge the importance of reflexivity as a researcher without necessarily displaying every detail to the reader. Researchers may simply acknowledge their presence, position, and influence on the research process in a short paragraph in the methods section of a paper or presentation. Alternatively, they may choose to discuss reflexivity in relation to the methodological evaluation of their study as a way of

demonstrating trustworthiness (Finlay, 2002b). The term trustworthiness is often applied when referring to the rigour of a qualitative study, since issues concerning reliability and validity are more quantitative constructs and are often difficult to measure in qualitative research (Creswell, 1998). Constructivist paradigms often use the criteria of credibility, transferability, dependability, and confirmability to establish trustworthiness in qualitative data, as compared to the criteria of reliability and validity which are associated with more quantitative approaches (Creswell, 1998; Denzin & Lincoln, 2000; Koch & Harrington, 1998; Lincoln & Guba, 1985).

In my study, creating transparency in the research process became an important step as a means of ensuring rigour and trustworthiness. By creating an audit trail (Creswell, 1998) and documenting the research process, I was able to make my thoughts, methodological decisions, personal values, and experience as a researcher visible to both myself and to the reader. A summary of findings was shared with the participants for comment and review, to help ensure that the results were reflective of the participants' experiences and not just my own interpretation based on my personal experience. This form of member checking is a common practice in qualitative studies to help enhance credibility (Creswell, 1998; Denzin & Lincoln, 2000).

### **Final Reflections: Taking a Mindful Approach to Research**

The goal of this paper was to bring to light some of the possibilities and practicalities of taking a reflexive approach to qualitative research by highlighting the ways in which I was able to incorporate reflexivity throughout my doctoral research and address some of the challenges of being reflexive. By exposing the backbone of my research design, my aim was to encourage researchers to dig deeper into their research

and to stress the importance and effect of critical self-reflection on the research design, data collection, data analysis, and the presentation of the research findings (Ortlipp, 2008).

It is recognized that the closer our subject matter is to our own life the more we can expect our own worldview to enter into and shape our work, to influence the questions we pose and the interpretations we generate from our findings. (Shah, 2006, p. 211)

Although it may be impossible to find answers to all of the reflective questions that arise throughout the research process, it is important to still discuss, acknowledge and document them in an effort to “stay intentional, conscious and transparent in amplifying and privileging the voices of study participants as authentically as was possible during the analysis of the research” (Valandra, 2012, p. 215).

*Mindfulness* is a concept most often associated with many spiritual, philosophical, and psychological traditions and refers to an alert awareness of self with an intentional focus on the present moment (Black, 2011; Fielden, 2010; Weick & Sutcliff, 2006). It is not a term often used in research; however, it is very relevant to the discussion of reflexivity and the need for an alert awareness of self throughout the research process (Fielden, 2010). Although definitions of mindfulness are continuously evolving and expanding, in this context it can be used to describe the process of actively paying attention on purpose, with purpose throughout the entire research process (Black, 2011; Fielden, 2010). Fielden (2010) states that mindfulness is an essential characteristic for qualitative researchers and can be a means of eliciting deeper meaning from the research and the researcher’s role as the main instrument for data collection. Qualitative



researchers also require mental flexibility to be able to analyze and adapt to the research as it progresses, and to help foster awareness and understanding of the perspectives of both the researcher and the researched (Weick & Sutcliffe, 2011). As Fielden (2010) argues, “the mindful researcher develops a greater self-awareness, understands the rational, emotional, spiritual, and psychological self in the process of knowing and in relationship to known facts” (p.46). Through mindful practice, the researcher can become more aware of their positionality within the research and the impact of their background, beliefs, values, experiences, and personal history on the research process and product. Researchers must practice this form of self-reflection and personal interrogation in order to uncover any underlying assumptions which may be present and to make them explicit to themselves and, in time, to the readers of the study (Mills et al., 2006a).

Among the many things learned and discovered throughout my doctoral research, the most poignant for me was my personal quest to find meaning as a researcher as I attempted to understand how others make meaning and sense out of their own worlds and experiences. As researchers, we continually strive to make meaning and sense out of a particular phenomenon, inductively or deductively analyzing situations and circumstances to find answers and explore the intricate contexts, causes, and consequences. However, for many researchers, there is often an individual quest or accidental discovery of meaning within the research context on a personal level as well. In essence, as a means of better understanding the experiences of others, we must take a mindful, reflective approach and examine the concept of meaning from both the participant and the researcher’s perspective.

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## **CHAPTER III**

### **Manuscript 2: Motivations for Cancer History Disclosure among Young Adult Cancer Survivors**

#### **Relationship of Manuscript 2 to the Dissertation**

This chapter is based on the main findings of this study looking at the disclosure decision process of young adult cancer survivors. This manuscript focuses on the motivations for cancer history disclosure and is situated within the approach and avoidance motivational goal framework. It also highlights some of the situational/contextual factors that contribute to young adult cancer survivors' disclosure decisions. This manuscript will be revised for submission to the *Journal of Cancer Survivorship*.

## **Introduction**

Cancer can have a profound effect on the overall well-being and quality of life for individuals of any age; however, young adults diagnosed with cancer often face additional challenges due to the disruption of many normative developmental tasks associated with this stage in life (Fernandez et al., 2011; Feuz, 2014; Zebrack, 2011). Young adulthood is often characterized as a time of change and transition as individuals work toward many important social milestones associated with adulthood such as forming intimate relationships, beginning a career, establishing financial and parental independence, and having children (Adolescent and Young Adult Oncology Progress Review Group [AYAOPRG], 2006; Miedema, Easley, & Hamilton, 2006; Warner et al., 2016). Although cancer in young adults is relatively uncommon compared to older adults, the impact is often disproportionately greater and can be particularly disruptive to social maturation, identity development, finding and maintaining effective social support, and establishing autonomy (Fernandez, 2011; Warner et al., 2016; Zebrack, 2007).

One of the most significant developmental tasks associated with young adulthood is the establishment of meaningful relationships; however, changes in friendships often occur after a cancer diagnosis for young survivors due to lengthy time away from home, school, or work due to treatment and the feeling that they no longer can relate to their peers (Howard et al., 2014; Miedema, Hamilton, & Easley, 2007; Zebrack, 2008; Barnett, Shuk, Conway, & Ford, 2014). Studies show that young adults with cancer often experience feelings of social isolation and have difficulty initiating new relationships after treatment (Barnett et al., 2016; Feuz 2014; Warner et al., 2016; Zebrack, 2000; Zebrack & Isaacson, 2012). In a focus group study conducted by Kent and colleagues



(2012), young cancer survivors indicated that changes to their social relationships and social roles after a diagnosis of cancer was their primary psychosocial challenge. Social interaction with peers is an important aspect of identity development in young adults and it is now widely recognized that social relationships can have a powerful effect on emotional wellbeing (Berkman, Glass, Brissette, & Seeman, 2000; Robinson, Miedema, & Easley 2014; Zebrack, 2007). Perceived and received social support can assist young cancer patients to feel less isolated and anxious, improving their overall outlook on cancer and quality of life (Kent et al., 2012; Miedema et al., 2007; Zebrack, Chesler, & Kaplan, 2010). However, cancer survivors often see a decrease in social support after the completion of acute treatments as they struggle to reintegrate back into their social world (Jones, Parker-Raley, & Barczyk, 2011).

Self-disclosure, the expression of personal details about oneself, is an essential component of interpersonal relationships and is often viewed as a necessary prerequisite for social support and preventing social isolation (Chaudoir & Fisher, 2010; Yoo, Aviv, Levine, Ewing, & Au, 2009; Gray, Fitch, Phillips, Labeacque & Fergus, 2000). The decision to disclose personal details to others involves an intricate negotiation process as individuals weigh both the potential risks and benefits of disclosure (Berg & Derlega, 1987; Greene, 2009; Omarzu, 2000). Individuals may experience benefits from self-disclosure as an expression of a new sense of self-identity, as a means of strengthening existing relationships and developing new ones (Knapp & Vangelisti, 1999; Munir & Griffiths, 2005). Communication with others can act as a means of coping for cancer survivors by giving them a sense of control after having experienced a great loss of control in their lives due to illness. On the other hand, potential risks may include the fear

of stigmatization, a fear of negative reactions or unsupportive behaviour, or even the fear of losing an opportunity for employment or friendship (Figueiredo, Fries, & Ingram, 2004). This disclosure decision process often becomes even more complex for individuals dealing with the effects of cancer or other chronic illnesses and disabilities (Hamilton & Zebrack, 2011). As Yoo and colleagues (2009) state, “telling others about illness takes emotional resources and opens one up to vulnerability, scrutiny and possibly rejection” (Yoo et al., 2009, p. 2).

Young adults may be particularly vulnerable to difficulties with self-disclosure after cancer. With the many personal and professional challenges after cancer treatment, the decision to self-disclose health history and the intricacies of when, to whom, and how to share this information with their family, peers, co-workers, new acquaintances, and potential intimate partners can have a major impact on their lives (Thaler-DeMers, 2001; Zebrack, Chesler, & Penn, 2007; Hilton, Emslie, Hunt, Chapple, & Zeibland, 2009). Because most healthy young adults have little experience with illness, peers may not know how to extend support and cope with a friend with cancer (Warner et al., 2016). It is also expected that young adult cancer survivors will go on to live long lives after successful treatment due to the young age of diagnosis, which means they may face these psychosocial issues for many years into long-term survivorship (Feuz 2014; Nathan, Hayes-Lattin, Sisler, & Hudson, 2011). Thus, it is important to examine the social impact of cancer on young adults and their self-disclosure processes in order to find better ways to provide support to address their unique needs as they attempt to redefine a sense of normalcy after treatment.

In a systematic review, Warner and colleagues (2016) found that few studies have focused specifically on the social well-being and the social experiences of young adults with cancer, especially compared with studies of older patients, or comparison groups of young adults without a history of cancer. They found that issues relating to interpersonal relationships or social interactions are often lumped together with other psychosocial and biomedical concerns such as managing distress and treatment side-effects (Warner et al., 2016). Although there is a growing body of literature on self-disclosure in general, few studies have focused on disclosure topics within the context of cancer, and even fewer on the experiences of young adults (Barnett, Shuk, Conway, & Ford, 2014). Much of the research to date related to self-disclosure and cancer focuses on the sharing of one particular piece of information such as a diagnosis (Checton & Greene, 2012).

Hilton and colleagues (2009) conducted a secondary gender-based analysis of narrative interviews with young adults diagnosed with cancer between the ages of 18 and 34 years of age in order to understand their experiences with disclosing their cancer diagnosis to family and friends. They found that most participants were open about their diagnosis; however, young men were more likely to be more secretive about their disclosure than women (Hilton et al., 2009).

Barnett and colleagues (2014) used a qualitative approach to examine cancer-related disclosure among survivors who were diagnosed between the ages of 14 and 21 years old. They identified three major themes: the complex process involved in the decision to tell (“it depends” decision-making process); the perception of others’ responses; and the method of disclosure (verbal, written, and behavioural). The results of their study emphasize the importance of peer relationships, possible interactions and

reactions, and the contextual factors (relationship potential, means of disclosure) that may impact cancer-related disclosure (Barnett et al., 2014).

Theories of self-disclosure in general exist in social psychology and communication research which describe disclosure decision models (e.g., Greene, 2009; Greene, Derlega, & Mathews 2006; Omarzu 2000) and factors that influence self-disclosure decisions. However, these theories do not provide much detail about participants' own description and explanation for their motivations for disclosure and few focus specifically on self-disclosure within the context of an illness or disability (Derlega, Winstead, Mathews, & Braitman, 2008). The purpose of this study was to explore the patterns of self-disclosure of cancer history among young adult cancer survivors and the impact these disclosure decisions had on their social reintegration after cancer and throughout their survivorship years. The goal of this article is to take an in-depth look specifically at the motivations and explanations for cancer history disclosure and/or non-disclosure from the perspective of these young survivors.

## **Methods**

### **Study Design and Sample**

Using a grounded theory approach, semi-structured telephone interviews were conducted with breast and testicular cancer survivors between the ages of 18 and 39 from across Canada, and who were at least 1 year post-diagnosis at the time of the interview. Grounded theorists aim to search for the processes and discover the patterns underlying human interaction in order to understand how a group of people define their reality through their social interactions (Cutcliffe, 2000). Specifically, I used a constructivist grounded theory approach which emphasizes the interactive relationship between the

researcher and the participants in the research process. This research paradigm focuses on the co-construction of meaning and brings the centrality of the researcher as author to the methodological forefront (Charmaz, 2000; Mills, Bonner, & Francis, 2006).

Breast and testicular cancer survivors were chosen for the following two reasons: 1) these two types of cancer have the highest incidence rates among young adults; and 2) both are similar in that they are highly associated with one's sexuality and sense of masculinity/femininity and therefore may present survivors with similar challenges to adjustment. I included survivors representing a wide time span in the survivorship phase in order to explore if disclosure patterns varied for those in the early years post-diagnosis (1-5 years) compared to those who were in the later years (6 years and over) of survivorship. Participants were required to have the ability to speak either English or French and to give consent. The study protocol was reviewed by the University of New Brunswick (File #2010-085) and the Horizon Health Network Research Ethics Boards (File #2010-1503).

Using a purposive sampling technique, participants were recruited from across Canada using a variety of methods. Recruitment information was sent to contacts at all young adult, testicular and breast cancer specific support organizations and support groups in each province and territory (where applicable); electronic recruitment information was sent out via e-newsletters (e.g., Young Adult Cancer Canada); online message boards (e.g., Kijiji); public forums; and through the social networking sites Facebook and Twitter. Interested participants were able to contact me via e-mail, Facebook, Twitter, or a toll-free phone number. In order to ensure a diverse sample of

participants and experiences, I then theoretically sampled to help refine emerging categories based on gender, province, and geographical location (urban/rural).

### **Data Collection**

Prior to the interview, participants were e-mailed a copy of the consent form and were invited to discuss any questions or concerns with me about the study. Procedures for oral consent were followed prior to the commencement of the interview. A semi-structured interview guide was used with questions designed to encourage participants to discuss their feelings and experiences in depth. The interview began with open-ended questions asking participants to describe their cancer experiences starting with the time leading up to the diagnosis through to where they were at the time of interview in their cancer journey. Probes were added to encourage participants to discuss any physical, psychological, and social issues experienced (e.g., sexuality, career, education, fertility, body image, financial). The second section of the interview included questions specifically about relationships, self-disclosure patterns, and motivations. The third section involved more existential questions about the impact and meaning of cancer in their lives and how or if having cancer had changed them in any way. The interview concluded with a question related to the experiences and any unique challenges of having cancer as a young adult. After the interview, socio-demographic information was collected to create a participant profile.

### **Analysis**

Interviews were digitally recorded, transcribed verbatim, and proofed. The transcripts were entered into the qualitative data analysis software program NVivo 9 (QSR International, 2010) to facilitate data management and coding. Following a

constructivist grounded theory approach, data collection and analysis took place concurrently allowing revisions of the interview guide to help refine emerging codes. Analysis involved line-by-line coding, with codes and categories emerging from participants' stories. Constant comparison was used to examine relationships within and across the various codes that emerged and to further refine the analysis (Charmaz, 2006). Participant recruitment concluded when theoretical saturation was achieved and no further themes or relationships between codes and categories were identified. Field notes and memos were kept in a personal research journal in order to capture my thoughts, early interpretations, and self-reflections in order to note any areas that needed further exploration.

### **Participant Profile**

A total of 28 young adult cancer survivors (16 female breast cancer survivors and 12 male testicular cancer survivors) participated in a telephone interview. The average age of the participants at time of diagnosis was 29 years old (Range 19-38; *SD* = 5.11) and the average age at time of the interview was 34 (Range 21-52; *SD* 6.98). Sixty-four percent of participants were 1-5 years post-diagnosis and 36% were 6 years and over post-diagnosis. The majority of participants (75%) were currently living in an urban area and just less than half (47%) had an annual family income of less than \$30,000 per year (see Appendix D).

### **Findings**

Based on the interviews conducted with young breast and testicular cancer survivors, cancer-related disclosure decisions were divided into three major themes: 1) motivations for disclosure; 2) motivations for non-disclosure; and 3)

situational/contextual factors influencing disclosure decisions. Researchers who study motivation and goal-oriented relational behaviour posit that two major motivational systems underlie most disclosure processes: approach-focused goals/motivations and avoidance-focused goals/motivations (Afifi & Guerrero 2000; Carver, 2006; Chaudoir & Fisher 2010). Individuals who are driven by approach-focused motivations are focused on the possibility of positive outcomes whereas those who are guided by avoidance-focused motivations are more focused on the avoidance of a negative outcome (Carver, 2006, Elliot, 2006; Chaudoir & Fisher, 2010). Chaudoir and Fisher (2010) argue that these disclosure goals affect the likelihood of disclosure in each situation. Some researchers claim that these approach and avoidance motivational systems are the fundamental building blocks underlying human behaviour (Carver, 2006; Chaudoir & Fisher, 2010; Ryan, 2006).

My analysis of the disclosure decision processes of young breast and testicular cancer survivors has been situated within this approach/avoidance goal framework. Overall, the participants in this study who expressed approach-focused motivations (towards a positive outcome) were more likely to disclose. Conversely, those expressing avoidance-focused motivations (towards a negative outcome) were less likely to disclose. However, the participants in this study described a series of situational/contextual factors which had the potential to change or influence the disclosure decision despite the overarching motivation to disclose or not. Figure 1 is a conceptual model depicting the interplay of factors influencing the disclosure decision process of young adult cancer survivors based on the findings of this study.



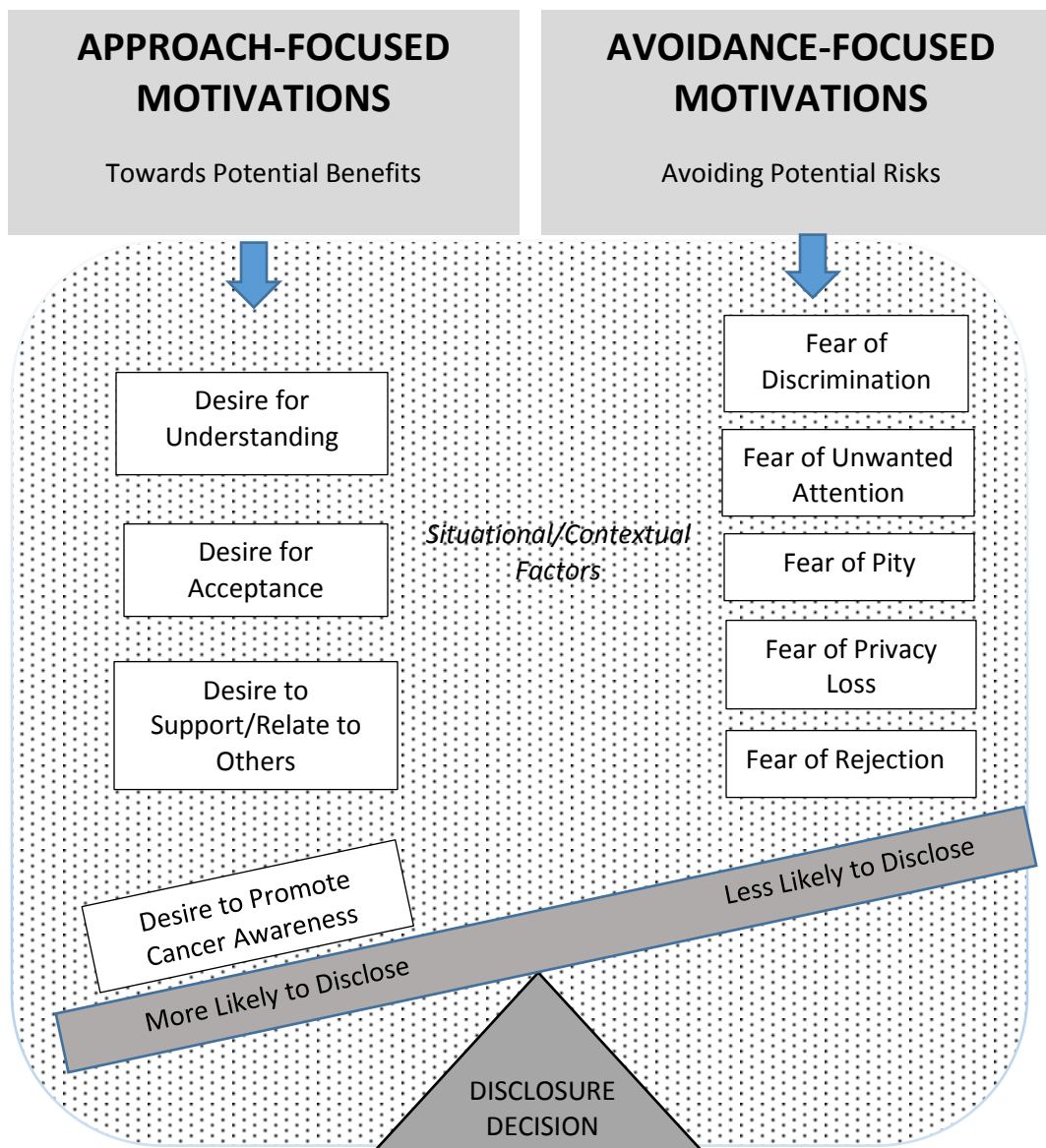


Figure 3.1. Motivations for cancer history disclosure of young adult cancer survivors.

### **Motivations for Disclosure (Approach-Focused)**

When participants were discussing the details of their disclosure decisions (if, when, how, why and to whom they disclose their cancer history), many expressed approach-focused motivations focusing on the positive impact and reaction they hoped to receive from the sharing of personal information (see Table 3.1). These approach-focused motivations influenced their decision to share their cancer history and most felt that disclosing gave them a sense of empowerment and control over their information.

*Desire for Understanding* was commonly expressed as a motivating factor for disclosure. These survivors felt that if they disclosed that they had a history of cancer and details of what issues they were facing due to cancer and the after-effects of treatment, the recipients of this information would have a better understanding of who they are and where they are coming from in terms of their thoughts and behaviours.

A number of participants also expressed a *Desire of Acceptance* which motivated them to move beyond just the desire for understanding to further look to their disclosure recipients to accept them as they are, which usually was in reference to more physical attributes (e.g., scars, fertility issues, sexuality issues). By disclosing these details up front to a person, these survivors felt it gave them the power and choice to further engage (or not) with this individual depending on his or her reaction.

Another common motivator for disclosure discussed by most of the participants was their *Desire to Support or Relate to Others*. In this case, participants felt compelled to disclose when they were talking with someone dealing with a similar situation, particularly if they were newly diagnosed. In many cases, the participants may not have initiated the cancer conversation but were prompted to disclose after the other opened up

about their experiences as a means of relating. Others shared their cancer history as a means of opening the door for support to the individual newly diagnosed.

A number of participants expressed a *Desire to Promote Cancer Awareness* and found that by disclosing their cancer history and sharing their experiences publicly they were able to help others on an even larger scale. The majority had the desire to bring awareness to cancer in young adults and often involved public speaking engagements, blogs, and articles written about their experiences, and cancer fundraising activities. Specifically, many testicular cancer survivors discussed a desire to bring awareness to their type of cancer because it involves an area of the body most are not comfortable talking about. They felt that their experiences at diagnosis would have been improved if they had more support and awareness of their cancer.

Table 3.1

*Illustrative quotes of motivations for disclosure (approach-focused)*

Sub-themes	Illustrative Quotes
Desire for Understanding	<p><i>“When I moved to this community I had this whole debate, do I tell people or not because I can start new, they don’t have to know me as ‘cancer girl’, you know. But I felt like I wanted them to know ...I need people to realize that I’m not this strange weird introverted person. I’m coping with a lot. I might not be able to have play dates over all the time because I might be tired, or you know, I wanted people to get that I wasn’t just lazy. I didn’t want to be judged...”</i> Interview 1: Breast Cancer</p> <p><i>“I feel there is a kind of special bond with the person I tell. I feel that they have a better understanding of my personality after telling them and they can understand why I act the way I do in certain situations.”</i> Interview 3: Testicular Cancer</p>
Desire for Acceptance	<p><i>“...I didn’t necessarily want to talk about it, but I felt I had to tell them [the girls I was dating] right away so there would be no surprises and they could hopefully accept me for who I am, all of me...This wasn’t always the case, but at least I didn’t waste too much time with the wrong girl”</i> Interview 11: Testicular Cancer</p>

Desire to Support or Relate to Others	<p><i>“One of the things that I found when I was diagnosed was there was almost a total lack of resources for young women with breast cancer. And I never want anyone to go through that again. So I have been very much the spokesperson. If anybody asks or if somebody who knows that I went through it knows somebody else who is going through it, I will make that contact.”</i> Interview 5: Breast Cancer</p> <p><i>“If I found out someone was going through something, even if I didn’t know them...I think that would usually trigger me to share that I also went through this difficulty and that I could relate”</i> Interview 3: Breast Cancer</p>
Desire to Promote Cancer Awareness	<p><i>“My goal isn’t to cure cancer, we can’t do it. But you know, nobody wants to talk about their nuts. Nobody wants to mention the word testicle...Nobody talks about testicular cancer, you know, so for me it was just getting the nuts word out there, just getting the testicular word out there for people to say...So, I’m very open about it...any time, any place somebody brings it up. I could almost wear a t-shirt that says ‘ask me about my nuts’ and I would talk to people about it, you know (laughs)”</i> Interview 9; Testicular Cancer</p> <p><i>“When my good friends started to find out [about my diagnosis] they started saying things like ‘man, if you could get it, anybody could get it...and now because of you all the women in my family are going to get tested’...And I realized, wow, if that’s the impact my diagnosis can have on my circle, what kind of impact can my diagnosis have if I allowed it to become public?...And for me I felt a real spiritual conviction...I was meant to do something with this and I was meant to do more.”</i> Interview 6: Breast Cancer</p>

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### **Motivations for Non-Disclosure (Avoidance-Focused)**

Reasons for not wanting to self-disclose involved many avoidance-focused motivations where avoiding a negative impact or reaction was the main goal (see Table 3.2). *Fear of Discrimination and/or Stigmatization* was an important factor that made survivors less likely to disclose and was predominantly discussed in relation to the workplace or job search. The fear was that if they disclosed their cancer history they would be seen as a less valuable employee or not capable of doing the job, or that they would feel stigmatized by their co-workers.

Related to this was the *Fear of Standing Out/Receiving Unwanted Attention*.

Many survivors did not want to disclose their cancer history to certain people because they did not want to stand out in any way and just wanted to fit in. They felt that as soon as the word cancer was mentioned that people would treat them differently, for better or worse. Many also expressed that they just did not want their health history to become the central focus of discussion and attention. They desired to have normal interactions with others and avoid having to go through the complex disclosure decision process of how to tell someone and if they should even bother telling them if it was not necessarily relevant. These participants were more likely to express a desire to move past cancer and to focus on other things.

*Fear of Pity* was a prominent sub-theme for those who expressed avoidance-focused motivations and were less likely to disclose. These participants did not want anyone to feel sorry for them in any way. The risk of telling someone and having them show any sign of pity was greater than any perceived benefit from disclosure. Pity, whether expressed openly or implied, was seen as a very negative sentiment and some survivors strongly stated that it made them feel weak or that they were viewed as somehow lesser because of their cancer experience.

*Fear of Privacy Loss* was expressed as the main motivating factor for a few survivors who really did not wish to share any of their cancer experience or issues with others and really wished to remain private. The participants who expressed this desire for privacy also noted that they were private about most details of their lives and even more so about something as personal as cancer.

One of the most common motivating factors discussed, predominantly in the context of dating, intimate relationships, was the *Fear of Rejection*. These survivors feared that they would not be accepted for who they are now post-cancer and that they felt too vulnerable to disclose their cancer history. This fear of rejection was closely related to issues involving sexuality and feelings of masculinity/femininity. It was mostly discussed in relation to new acquaintances or people they were getting to know on a more personal level of friendship and was most frequently mentioned by participants who were in the early years of survivorship (1-5 years post-diagnosis).

Table 3.2

*Illustrative quotes of motivations for non-disclosure (avoidance-focused)*

Sub-theme	Illustrative Quotes
Fear of Discrimination and/or Stigmatization	<p><i>“...the one situation I would feel very reluctant to share is at my workplace. I think because I am very concerned about discrimination. I mean, even though now I do have a job, but you never know. I may be switching jobs in the future and I sort of don’t want people in this industry, I don’t want it to be very well known in this industry that I had cancer, because I’m concerned about discrimination”</i> Interview3; Breast Cancer</p> <p><i>“...If I were to apply for any other jobs that were not health related I definitely wouldn’t disclose this unless it came up because...people might not hire me”</i> Interview 11; Breast Cancer</p>
Fear of Standing Out/Receiving Unwanted Attention	<p><i>“I found a job in the paper...I didn’t tell them what I had been through [cancer history]. They hired me, they trained me...and I just kept my mouth quiet...There were about 4,000 people working there at the time and I just wanted to be the same. I didn’t want to be treated differently and I didn’t want to stand out in any way, uhhm...I just wanted to be less than obvious. I just wanted to feel like I was just part of the rest of that crew”</i> Interview 4:Testicular Cancer</p> <p><i>“I just wanted to be one of the guys, you know, just shooting the shit in the locker room like everyone else. I didn’t want the stares, the questions... I just kept to myself... I just wanted to be the same as everyone else.”</i> Interview 11: Testicular Cancer</p>

Fear of Pity	<i>“When I was first diagnosed at 23, my first instinct was ‘how can I keep anybody from knowing?’ and the reason for that for me was that I didn’t want people feeling sorry for me. I’ve always been highly independent and self-confident and driven and motivated and ambitious and I didn’t want people to see me as weak. I didn’t want people to see me as I’m not able, or I didn’t want people to feel sorry for me”</i> Interview 6: Breast Cancer
Fear of Privacy Loss	<i>“I just get tired of being on display all the time...I feel exposed and like pretty much everyone knows so much about me already because of my cancer and being so young. People I don’t even know have come up to me and said they heard about what I went through....Like seriously, sometimes I just crave privacy and for everyone to just stop talking about my personal business.”</i> Interview 12: Testicular Cancer
Fear of Rejection	<i>“I hate the idea of telling a new partner my history and all my, like, sexual issues and all my scars, you know, because I’m afraid of being rejected for something that isn’t even my fault. Easier just to avoid it [dating] all together”</i> Interview 2: Testicular Cancer

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### **Situational/Contextual Factors Influencing Disclosure Decisions**

In this study, three participants claimed they almost always disclose their cancer history and two stated that they rarely disclose to anyone. However, the majority of participants stated that their disclosure decisions varied and certain factors often influenced these decisions in any given moment no matter the overarching motivations to disclose or not (see Table 3.3).

*Social/Cultural Context* was relevant to the disclosure decision for some participants, in that they felt there were times when it was not socially appropriate to disclose their cancer history and details of their experiences or it was not always appropriate in their family culture. This was mainly in reference to the fact that many people in their environment are not comfortable discussing “private parts” (i.e., breasts or testicles) with others.

*Relevance* was an important factor discussed that often impacted the likelihood of disclosure. Many participants discussed that even if they may want to disclose something related to their experience, or wanted people to know that they had cancer, it was not always relevant to the conversation and therefore was not easy to bring up.

*Situation/Timing* was also an issue for many, as they discussed that there was no real perfect timing or an ideal situation to disclose such personal information to someone. A few mentioned that they felt that due to their young age at diagnosis their cancer disclosure often carried an additional weight of the shock and disbelief from recipients as cancer is not expected at that stage of life.

As expected, many disclosure decisions are dependent on the *Person Disclosing*, their individual personality and their thoughts and feelings at any given moment. Also relevant are the socio-demographic characteristics of that person and their personal background. In this study, there were no clear differences between disclosure patterns of males and females. Age at time of diagnosis was a factor as the younger people in this study were less likely to be in a secure relationship or have stable employment and therefore had to make more disclosure decisions related to dating and seeking employment. It is unclear whether ethnicity had an impact on disclosure patterns as the study sample was predominantly Caucasian, despite theoretical sampling efforts. Being in a relationship versus being single impacted the experiences and attitudes towards disclosure in relation to sexuality and dating, as was expected. Being in a relationship did not necessarily discount body image issues or problems with sexuality and intimacy, it was however more likely to influence their comfort in and opportunity to disclose these issues compared to someone who was dating or starting a new relationship. For work-



related disclosures, those who were employed had less problems disclosing to their employers and colleagues where there was a perceived network of support in place and their job was not at risk. However, for those who were not in a permanent position, looking for work or had to change work due to cancer-related issues, the disclosure process was much more complex as they weighed the need to tell versus the fear of discrimination. For young survivors in rural areas, decisions to share or withhold information were often pre-empted by the fact that news of their diagnosis was already known throughout their community. This provided a great sense of support for some, while for others they felt it limited their choice to remain private. However, all rural participants did state that it was an expected part of living in a rural community where social networks were close-knit.

Disclosure decisions were also influenced by the *Audience/Confidant*. All of the survivors mentioned that their decision to disclose or not depends largely on the person with whom they are interacting. For most people, a trusting relationship is formed before they chose to disclose, with the exception of situations which may require disclosure such as a job interview or in the workplace.

Finally, an important contextual factor related to disclosure is the *Time Passed Since Cancer Diagnosis*. In this study, those in the earlier years of survivorship (1-5 years) seemed to struggle a bit more with the complexities of the disclosure decision process. Many expressed a need to share their story as part of the healing process, and felt that they were struggling with several issues related to their cancer experience that impacted their thoughts, feelings, and behaviours. It seems the longer the time passed since diagnosis, the less relevant the cancer history seemed to be to their everyday lives.

For long-time survivors, most people in their immediate circle of friends, family, and workplace were already aware of their cancer history and there seemed to be less of a desire to discuss their history with new acquaintances or in regular conversation. They were further along in the quest to regain or redefine normalcy and seemed to have come to more of an acceptance of their current realities or most had found ways to cope with any challenges or limitations.

Table 3.3

*Illustrative Quotes of Situational/Contextual Factors Influencing Disclosure Decisions)*

Sub-theme	Illustrative Quote
Social/Cultural Context	<p><i>“In my family, we just don’t talk about things like that [our health]...men don’t talk about their feelings, and we certainly don’t talk about our bodies, especially our nuts!! (laughs)... that’s just how I was brought up.”</i> Interview 12: Testicular Cancer</p> <p><i>“I guess sometimes I just have to step back and assess whether or not I think it is socially acceptable or appropriate to tell people I had breast cancer, you know... Like, it isn’t always cool to just drop the ol’ c bomb in a group of people you hardly know or a bunch of your mother’s church lady friends (laughs)”</i> Interview 16: Breast Cancer</p>
Relevance	<p><i>“In terms of a stranger, I guess it wouldn’t come up, unless say, if they brought something up about cancer if it was relevant somehow then I would start talking about it.”</i> Interview 1: Breast Cancer</p> <p><i>“It is not something that I hide. It’s more or less on a need-to-know basis...If it comes up, I’m more than happy to talk about it, but it’s not something that I go around bragging about.”</i> Interview 2: Testicular Cancer</p>
Situation/Timing	<p><i>“For me, the biggest challenge is finding the right time and situation to tell someone...I don’t want to just blurt it out any old time, yet at the same time I feel it is important for them to know that about me...you know, you just take the path of least resistance and just find a time that is most right and go from there”</i> Interview 10: Testicular Cancer</p>

Person Disclosing	<p><i>“Sometimes you feel very vulnerable and you really don’t want to discuss it and then other times you are fine.”</i> Interview 2: Breast Cancer</p> <p><i>“I think a lot depends on your personality and who you are. I found that by telling everybody that it made it easier. Because when everybody knew you weren’t trying to tiptoe around people or hiding.”</i> Interview 10: Breast Cancer</p>
Audience/Confidant	<p><i>“I think it depends on how comfortable I am with that person...like you know if I feel like he or she is someone I can trust and I feel that we can establish a long-term friendship, then I would tell them”.</i> Interview 3: Breast Cancer</p> <p><i>“There are certain people you get to know after a while that you know how they’re going to handle things. And you know which ones you can kind of lean on, or which ones you can’t.”</i> Interview 5: Breast Cancer</p>
Time Passed Since Cancer Diagnosis	<p><i>“I feel less compelled to tell people now than I did early on, I think because it was so much my whole existence then, so like, how could I say how I was when I was home recovering if I didn’t talk about it. And now...I can go a day and sort of forget that I had cancer. So I don’t feel as compelled to sort of talk about it because it doesn’t affect my daily life”</i> Interview 4: Breast Cancer</p> <p><i>“As time has passed since my diagnosis I find it more and more unnecessary to divulge my cancer diagnosis...Not that I want to keep it secret from others just that it is not a topic of general conversation”</i> Interview 3: Testicular Cancer</p>

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## **Discussion**

The findings of this study highlight the complexity of the disclosure decision processes of young adult cancer survivors. Analysis of these interviews with young breast and testicular cancer survivors revealed two basic motivational systems for disclosure at play: approach-focused motivations geared towards a positive outcome (*understanding, acceptance, support, awareness*) and avoidance-focused motivations which are geared towards avoiding a negative outcome (*discrimination/stigmatization, unwanted attention, pity, loss of privacy, rejection*). Those exhibiting approach-focused motivations were

more likely to disclose than those expressing avoidance-focused motivations. This finding is consistent with other models of self-disclosure which suggest that people weigh or balance the pros and cons of disclosure and that reasons for disclosure focus on rewards (e.g., catharsis, social support) and reasons for not disclosing focus on costs (e.g., shame, embarrassment) (Afifi & Steuber, 2009; Checton & Greene 2012; Derlega et al., 2008; Greene, 2009, Greene et al., 2006; Omarzu, 2000). Further, Chaudoir and Quinn (2010) found that if cancer survivors had received a negative reaction and response early on in their cancer journey they were less likely to disclose in the future. These motivations for disclosure often change based on personal, social, cultural, and relational contexts (Afifi & Guerrero, 2000). Although other studies have found differences in disclosure patterns of male and female participants (Barak & Gluck-Ofri, 2007; Consedine, Sabag-Cohen, & Kirvoshekova, 2007; Kameny & Bearison, 2002; Yoo et al., 2009), gender was not a prominent factor in this study. This is perhaps due to the fact that this was a qualitative study and more likely to attract participants who are willing to share the details of their cancer experiences in general, regardless of gender. Similarities between the male and female participants may also be related to the nature of their cancer types in that they bear similarities in the fact that they may have an effect on sexuality and an individual's sense of femininity or masculinity.

The most pervasive motivations for disclosure or non-disclosure discussed among the young survivors in this study was the desire for acceptance and understanding (disclosure) and the fear of rejection and discrimination (non-disclosure). These motivations for disclosure or non-disclosure are strongly related to concept of belongingness. According to many scholars in the field of social psychology, the need to

belong is a fundamental social motive that can have a great influence on human behaviour, emotion, and thought (Baumeister & Leary, 1995; Leary & Cox, 2008; Walton, Cohen, Cwir, & Spencer, 2012). As Baumeister and Leary (1995) posit, “human beings have a pervasive drive to form and maintain at least a minimum quantity of lasting, positive and significant interpersonal relationships” (p. 497). Researchers have shown that positive interpersonal relationships and a general sense of belonging can have a profound impact on well-being and meaningfulness in life (Lambert et al., 2013; Walton et al., 2012). This is particularly important for young adults diagnosed with cancer. Cancer can be disruptive at any age; however, in young adulthood the diagnosis of cancer can have a profound impact on social relationships during a time and stage of life when these connections, both personally and professionally, are just being established (Robinson, Miedema, & Easley, 2014).

These prominent motivators for disclosure (desire for acceptance and understanding) or non-disclosure (fear of rejection and discrimination) were particularly salient for participants who were earlier in the survivorship phase (1-5 years post-diagnosis). Cantrell and Conte (2009) discuss a phenomenon that sometimes happens for young cancer survivors in early years of survivorship where they are caught between a cancer identity and a survivor identity as they transition post-treatment. They no longer identify with those who are “sick,” yet they do not feel well enough to be considered part of the “healthy” group (Cantrell & Conte, 2009). Jones and colleagues (2011) further this point by noting that these identity struggles in the early years post-treatment can create and exacerbate feelings of isolation and emphasize their need to belong. For young cancer survivors, the quest to regain normalcy after treatment can be especially

challenging when their sense of normal had not even been established prior to being diagnosed with cancer (Miedema et al., 2007). Many survivors are still processing the cancer diagnosis in the first few years post-treatment while trying to recover and cope with the physical and psychosocial impact of cancer and its treatment. Participants who were later in the survivorship phase were often less inclined to feel the need to disclose their cancer history and generally found their experiences less relevant to their day-to-day lives. This is possibly related to the fact that most had (re)established some sense of normal post-cancer and were more likely to be involved in stable relationships and more secure employment. Gray and colleagues (2000) also found that disclosure patterns changed over time. In their study of men with prostate cancer, one year after surgery few men were disclosing much at all about their health to anyone other than their spouse, even those who originally were willing to disclose more in the beginning.

Control and power are two attributes that are often challenged when a person is diagnosed with cancer. According to Charmaz (1991), when an individual dealing with an illness chooses to disclose personal information they risk losing control of their identity, control over information, control over emotions, and control over their lives. Self-disclosure is often a way for patients and survivors to regain some sense of control during a time when they may feel like they have so little due to cancer (Charmaz 1991; Donovan-Kicken, & Caughlin, 2011). For those who choose not to disclose, controlling communication about cancer preserves a sense of privacy which can help decrease feelings of vulnerability and increase feelings of autonomy and control (Donovan-Kicken & Caughlin, 2011; Margulis, 2003). In this study, many participants chose to partake in what Charmaz (1991) calls *strategic announcing* as a means of taking control after

cancer. This act often involved public speaking, blogging, and writing books and articles about their cancer experiences for the purpose of creating awareness of breast or testicular cancer in young adults. These survivors hoped their willingness to share their cancer experience would have a positive outcome of better support networks and programs for those newly diagnosed or diagnosed in the future. Participants claimed that publicly speaking about their cancer experiences felt empowering and gave them a sense of control which helped to make them feel less vulnerable. Charmaz (1991) states that this form of informing or strategically announcing permits “greater control over emotions, over others’ responses, and over possible negative labels.” (p. 121).

Social relationships and intimacy are particularly important developmental aspects of young adulthood and self-disclosure is an essential component in the development and strengthening of these relationships (Barnett et al., 2014; Jourard, 1971). An overall sense of support induced through self-disclosure and social inclusion has been found to enhance the psychological well-being and coping abilities of those faced with an illness or disability (Figueiredo et al., 2004; Munir et al., 2005). Research has shown that individuals who focus on the potential for positive outcomes (approach-focused goals) experience better social outcomes than individuals who view their relationships in terms of their potential for negative outcomes (Chaudoir & Fisher 2010; Elliot, Gable, & Mapes, 2006; Gable, 2006). Future research is needed to help further our understanding of the negotiation processes involved in deciding to reveal or withhold personal information to others in order to help provide better support for this underserved and often overlooked population of young adult cancer survivors. A longitudinal study would be particularly useful in exploring disclosure decisions over time in this population

and how the interplay of factors (belongingness, control, self-identity, normalcy, acceptance) and time since diagnosis affect the decision process.

### **Impact for Cancer Survivors**

This study focuses on the specific motivational goals (approach and avoidance) that influence self-disclosure after cancer and the contextual factors that influence these disclosure decisions among young adult cancer survivors. Recognizing the importance of belongingness in this population and the ways in which young cancer survivors control and manage information about their cancer history, emotions, and experiences is essential to designing and implementing support interventions to help young survivors as they attempt to reintegrate back into personal and professional life following cancer treatment.



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## CHAPTER IV

### **Manuscript 3: Self-identity and illness centrality after cancer: The experiences of young adult cancer survivors**

#### **Relationship of Manuscript 3 to the Dissertation**

This chapter focuses on one of the prominent themes that emerged from the findings—self-identity and illness centrality after cancer. It highlights some of the ways in which young adult cancer survivors (re)construct, redefine, and/or embrace their identities post-cancer and how they situate their cancer experience within their overall self-concept. The chapter also shows how illness centrality can play a key role in this process of identity (re)construction and highlights how cancer survivors often place different weights of importance on their cancer experiences as they move forward with their lives. This manuscript will be revised for submission to the *Journal of Psychosocial Oncology*.

## Introduction

Cancer and its treatment can affect an individual in many ways beyond just the physical. Cancer survivors often experience long-term psychological effects such as body image issues; fear and anxiety about the cancer coming back; depression; and feelings of uncertainty and isolation (Barnett et al., 2016; Bleyer & Barr 2009; Zebrack, 2008).

Cancer can also impact an individual's sense of identity and self-concept, as well as how they view and experience their lives (Zebrack, 2000). The experience of life after cancer involves a certain level of identity (re)construction or changed construction as survivors attempt to resume a version of their former lives within the context of the changes they have experienced and the insights they have gained (Fife, 1994; Little, Paul, Jordens, & Sayers, 2002; Zebrack 2000). For young adults with cancer, this may be a challenge as their sense of *normal* or place in the social world may not have had a chance to be established prior to diagnosis (Miedema, Hamilton, & Easley, 2007).

Young adulthood is a very transitional and challenging stage of life as individuals navigate their way through the many developmental tasks associated with becoming an adult, such as establishing autonomy, dating, pursuing education, starting a family, and striving to start a career (Kumar & Schapira, 2012; Miedema, Easley, & Hamilton, 2006; Zebrack, Chesler, & Penn, 2007). It is also during the adolescent and young adult years that an individual really defines his or her sense of self in relation to others (Feuz, 2014; Harter, 2011; Tindle, Denver, & Lilley, 2009). The conception of self broadens during the adolescent and young adult years in congruence with the expanding number of roles and new experiences (Feuz, 2014; Harter, Bresnick, Bouchey, & Whitesell, 1997). These normative developmental life tasks and processes of identity formation may be disrupted

and/or heavily influenced by a major event such as a cancer diagnosis (Grinyer, 2007; Helgeson & Novak 2007; Tindle et al., 2009).

Young adult cancer survivors often attempt to relate their prior conceptions of normalcy to their current reality of life after cancer as a way of coming to terms with their diagnosis and treatment (Kumar & Schapira, 2012). Cantrell and Conte (2009) described how many young cancer survivors end up in an identity paradox where they are stuck between not being sick any more, yet not fully healed and restored to their former capacity and capabilities. They state that part of the struggle for young cancer survivors is “to comprehend how to incorporate the loss and the effects of treatment into their identity as well as the gains they have realized from the experience” (Cantrell & Conte, 2009, p. 317). In their qualitative study, Kumar and Schapira (2012) found that young adult cancer survivors tend to reconcile their lives before and after cancer by either separating their past and present identities, or by attempting to restore some kind of linearity between their pre- and post-cancer experiences (Kumar & Schapira, 2012). The meanings that emerge from the cancer experience as well as the individual’s ability to reconcile any differences between his or her ideal and actual experience post-treatment can be a factor in the overall adjustment after cancer (Jones, Parker-Raley, & Barczyk, 2011; Zebrack, 2000).

Defining self-identity is a complex task as there is no single, universally accepted definition and the constructs of identity formation vary widely among behavioural and social scientists (Leary & Tangney, 2012). For example, sociologists tend to focus more on the social experience in the production of identity as opposed to social psychologists who focus more on the internal cognitive processes and personality traits involved

(Leavey & Kelleher, 2004). This does not mean that these factors are ignored in either discipline, rather the disciplinary focus is on one aspect more than another (i.e., social vs. personal) in the analysis of identity formation (Kelly & Millward, 2004). The terms *self*, *identity* and *self-concept* are often used interchangeably; however, Oyserman, Elmore, & Smith (2012) suggest that these concepts should be considered as nested elements, where “self-concepts are embedded within the self, and identities are embedded within self-concepts” (p. 94).

Kelly and Millward (2004) distinguish between two types of identity: that which relates to self (private) and that which relates to others (public or social). The private self exists internally, whereas the public or social identity exists in the minds of others (Little et al., 2002). Collectively, these private and public identities include the “traits and characteristics, social relations, roles, and social group memberships that define who one is” (Oyserman et al., 2011, p. 69). From a symbolic interactionist perspective, self-identity is socially constructed and reflects one’s interactions with other individuals and the world around them (Belizzi & Blank 2007; Oyserman et al., 2011; Zebrack, 2000). As such, identity formation can be modified by events and life experiences that happen along the way (Little et al., 2002). Oyserman and colleagues (2011) point out that “self and identity researchers have long believed that the self is both a product of situations and a shaper of behaviour in situations” ( p. 70). Individuals vary in the degree to which they incorporate their illness experiences into their self-concept, with some people defining themselves in terms of their experiences and others choosing to separate their self-concept from the rest of their lives (Charmaz, 1995; Park, Bharadwaj, & Blank, 2011).

Despite the recognition that cancer and its treatment can have a profound effect on an individual's sense of self, little is known about the formation of post-cancer identities and how the cancer experience becomes integrated into an individual's self-concept (Helgeson, 2011; Kumar & Schapira, 2013; Park et al., 2011). The term *illness centrality* has been used to describe the extent to which people define themselves in terms of their illness (Helgeson, 2011; Helgeson & Novak, 2007; Park et al., 2011). Studies on identity after cancer focus mostly on how cancer survivors identify and label themselves after cancer as being either a "survivor," "patient," "victim," or "person with cancer," and not as much on how the illness experience is incorporated into the rest of their lives (Park, Zlateva, & Blank, 2009). Park and colleagues (2011) speculate that post-cancer identity may be less defined by a particular label adopted and attributed more to illness centrality and the extent to which one's concept of self is now situated within the context of the cancer experience (Parks et al., 2011). Illness centrality can have an impact on health outcomes depending on whether the individual perceives the illness in positive or negative terms (Helgeson & Novak, 2007). For young adults diagnosed with cancer, illness centrality may play a key role in how they define themselves post-cancer as they embark on the process of defining and/or redefining their sense of normalcy at a time in their lives when their sense of normal may not have been previously established.

The goal of this article is to highlight some of the ways in which young adult cancer survivors (re)construct, redefine, and/or embrace their identities post-cancer and how they situate their cancer experience within their overall self-concept. This analysis is based on the results from a study looking at the patterns of self-disclosure among young adult cancer survivors. Self-identity and illness centrality emerged as major themes

relating to how these young adults situated themselves in relation to others and the motivations for disclosing or not disclosing information about their cancer histories. For this analysis, I have taken an interdisciplinary approach using a very fluid definition of self-identity to encompass all aspects of how an individual sees him or herself and how they see themselves in relation to others, focusing specifically on how these young adults situate their illness experiences into their post-cancer identities. For this paper I will use the term *cancer survivor* to describe these participants who were all at least one year post-diagnosis and were all comfortable with the use of the term.

### **Methods**

Using a grounded theory approach, I conducted semi-structured telephone interviews with breast and testicular cancer between the ages of 18 and 39 years from across Canada who were at least 1 year post-diagnosis at the time of the interview. I included survivors representing a wide time span post-treatment in order to explore whether or not cancer experiences varied for those in the early years post-diagnosis (1-5 years) compared to those who were in the later years (6 years and over) of survivorship. Breast and testicular cancer survivors were chosen because these two types of cancer have the highest incidence rates among young adults and both are similar in that they are highly associated with one's sexuality and sense of masculinity/femininity and therefore may present survivors with similar challenges to adjustment. Participants were required to have the ability to speak either English or French and to give consent. The study protocol was reviewed by the University of New Brunswick (File #2010-085) and the Horizon Health Network Research Ethics Boards (File #2010-1503).

Participants were recruited using a variety of methods. Recruitment information was sent to contacts at all young adult, testicular- and breast cancer-specific support organizations and support groups in each province and territory (where applicable); electronic recruitment information was sent out via e-newsletters (e.g., Young Adult Cancer Canada), online advertising and message boards (e.g., Kijiji), public forums and through the social networking sites Facebook and Twitter. In order to ensure a diverse sample of participants and experiences, I then theoretically sampled to help refine emerging categories based on cancer type, province, and geographical location (urban/rural). However, sampling was slightly constrained by the parameters of the self-referral nature of the recruitment strategy. Interested participants were able to contact me via e-mail, Facebook, Twitter or a toll-free telephone number.

Prior to the interview, participants were e-mailed a copy of the consent form and were invited to discuss any questions or concerns with me about the study. Procedures for oral consent were followed prior to the commencement of the interview. A semi-structured interview guide was used with questions designed to encourage participants to discuss their feelings and experiences in depth. Interviews were digitally recorded, transcribed verbatim, and checked for accuracy. The transcripts were entered into the qualitative data analysis software program NVivo 9 (QSR International, 2010) to facilitate data management and coding.

Data collection and analysis took place concurrently allowing revisions of the interview guide to help refine emerging codes. Analysis involved line-by-line coding, with codes and categories emerging from participants' stories. Constant comparison was used to examine relationships within and across the various codes that emerged and to

further refine the analysis (Charmaz, 2006). Participant recruitment concluded when saturation was achieved and no further themes or relationships between codes and categories were identified. Specifically, I used a constructivist grounded theory approach, which is based on the epistemological underpinnings of constructivism. Constructivism holds that people confer meaning onto their lived experiences by virtue of a complex intermingling of individual and collective past experiences that provide context. A constructivist grounded theory approach allows researchers to be actively involved in the data collection process as they interact with participants asking questions and inviting clarification or elaboration on different aspects of the communication (Charmaz 2006; Hall & Callery, 2001; Mills, Bonner, & Francis, 2006). Field notes and memos were kept in a personal research journal in order to capture my thoughts, early interpretations, self-reflections, and areas that needed further exploration.

To ensure the overall rigour of the study, the following steps were taken: a literature review; memoing and reflective note taking throughout the entire research process; a detailed trail of methodological decisions (audit trail); systematic data coding and analysis; and use of direct quotes so that the perspectives of the participants are represented as clearly as possible. A summary of the findings was shared with participants for comment and review. Only positive comments were received from those participants who responded.

## **Findings**

Sixteen breast cancer survivors (female) and 12 testicular cancer survivors (male) participated in this study. The average age of the participants at time of diagnosis was 29 years old (Range 19-38; SD 5.11) and the average age at time of the interview was 34



(Range 21-52; SD 6.98). Sixty-four percent of participants were 1-5 years post-diagnosis and 36% were 6 or more years post-diagnosis. The majority of participants (75%) were currently living in urban areas and just less than half (47%) had an annual family income of less than \$30,000 per year (see Appendix D).

Participants were asked a series of open-ended questions asking them to describe their cancer experiences from the time leading up to their diagnosis through to where they were at the time of the interview in their cancer journey. Questions were asked about their relationships and their motivations for disclosure (or non-disclosure) of their cancer history to others. The final part of the interview involved more existential questions about the impact and meaning of cancer in their lives and how or if having cancer had changed them in any way. Identity and illness centrality emerged as prominent themes throughout the entire interview, particularly in relation to the final questions relating to meaning and changes after cancer.

### **Identity Shifts**

**Loss of identity.** When describing the ways in which their lives had changed since being diagnosed with cancer, many young adults (particularly female survivors) described feeling a loss of identity. On a personal level, some survivors felt that they could no longer identify with their former selves and with the social roles (e.g., family or work roles) that used to be a major part of their identity as this cancer-related identity came to the forefront. As one breast cancer survivor describes:

*“I felt a huge loss of identity. I felt, first of all, when I became a mother I lost my identity of being a teacher. And then when I got sick I couldn’t even mother, and then I lost my hair and I didn’t even look like myself and it was like loss upon*

*loss, you know? ...So I feel like it is a different person in the mirror.” (Interview 1; Breast Cancer)*

Loss of identity was experienced by some participants more in a social context, as other people tended to focus predominantly on the cancer experience instead of all other aspects of their identity. A young breast cancer survivor describes her experience as follows:

*“Somebody said to me one time, ‘well all anybody knows about you is that you’ve had breast cancer’... And I said, ‘but I’m not ashamed of that’... But, this was somebody I felt that kind of knew me, and I thought ‘really? Like, you, you really don’t see all the other facets of who I am, and all that I have to offer. And, all the other parts of my personality and my good character traits, and my um, work ethic and all those things right?’... So I was upset by that comment.” (Interview 6; Breast Cancer)*

Both within these social and personal contexts, this loss of identity was seen as a negative consequence as these survivors struggled to come to grips with other losses from cancer such as the loss of control, loss of friendships, loss of mobility and loss of hair due to chemotherapy treatments. In this context, survivors felt that they were not given the option to choose their identity, rather it was imposed on them (either by themselves or by others) because of their cancer experience.

**“The one who had cancer...”**. Further to the loss of identity, many participants stated that people regularly refer to them by this cancer identity when talking to others, whether the survivors wanted them to or not. Repeatedly, survivors in this study claimed that they were referred to in public as “the one who had cancer.” In many cases, this

public *cancer identity* was emphasized by the fact that these young adults were diagnosed at such an early age, making their situation even more noteworthy to others. As one participant described<sup>1</sup>:

*“There are so many people in my life who know me as ‘Jenny that had breast cancer when she was in her early thirties’.”* (Interview 5; Breast Cancer)

Although it was acknowledged that the overall intentions of the people making these public proclamations about their cancer history were mostly good, it was not always welcomed or well received by the survivors. In many cases, participants stated that it made them feel like they were on display and that their lives were subject to comment, whether they identified themselves in terms of their cancer experience or not. A breast cancer survivor described it as follows:

*“I just find it funny that I’m introduced sometimes by things as ‘this is the girl I was telling you about who has cancer’. And it’s like that really doesn’t define me.”* (Interview 11; Breast Cancer)

A testicular cancer survivor describes how being publicly labeled as a cancer survivor can make it hard to move away from that cancer identity.

*“You can try to move on but when you keep being singled out by people as ‘the guy who had cancer in his 20s’ then it becomes pretty difficult to be anything else”* (Interview 10; Testicular Cancer)

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<sup>1</sup> Names have been changed to ensure confidentiality

## **Illness Centrality**

As participants discussed the impact of cancer on their lives and their motivations for self-disclosure, a very distinct theme emerged related to how these young survivors situate their cancer experiences into their current lives. This concept, referred to by researchers as illness centrality (Helgeson & Novak, 2007; Park et al., 2011), was a common thread that ran through all of the interviews. Without being prompted, participants were almost entirely divided into two distinct groups: those that incorporated cancer into their current identities as a major part of who they are now, and those who felt that cancer was just something that happened to them and did not define them. Although there was variation in the degree to which these survivors discussed this centrality, there was definitely evidence of a process of negotiation that happens as a means of situating their cancer experiences into their new post-cancer identities.

**“Cancer is just part of who I am now...”**. Just less than half of the survivors interviewed (43%) stated that they have incorporated their cancer experiences into their newly defined self-identity. These participants would often state the words (or some variation) “it’s just part of who I am now”. As one breast cancer survivor described:

*“I have a class reunion coming up in a couple of weeks...Like, there are people in that class that I haven’t seen in years who wouldn’t know that I went through stuff, but I feel like, you know, when people say ‘oh, so what have you been up to the last 20 years’ and it’s like, I was thinking, like, it will probably come up, because that’s part of who I am now, right?”* (Interview 1; Breast Cancer)

The ways in which participants situated their cancer into their current lives had a big impact on their disclosure decisions. These participants with a higher degree of illness

centrality were more likely to disclose their cancer history to others. As the following breast cancer survivor states:

*“Somebody just contacted me on Facebook that I haven’t seen in like ten years, and so we just started communicating back and forth, so she doesn’t know what has happened, and I hate the thought of like having to go there [self-disclose]...but I will [tell her] because I feel like it is just who I am now and it is part of my experience.”* (Interview 4; Breast Cancer)

The centrality of the cancer experience for these survivors was not only discussed by the female participants, many testicular survivors also discussed how cancer has been incorporated into their identity. For the males, this was often discussed in relation to their experiences with dating and starting new relationships. As one testicular cancer survivor stated:

*“I’ve got no issues at all scar wise or like, body image sense in that way. And just basically, this is what happened, this is who I am now and that’s basically it. It was sort of a putting all the cards on the table and if you can deal with it great, and if you can’t oh well.”* (Interview 1: Testicular Cancer)

Another testicular cancer survivor described his experience disclosing his cancer history on a first date, and how it relates to the centrality of his cancer experience:

*“But yeah, on our first date we talked about it [testicular cancer diagnosis]. You know, I told her all about it and stuff. So, it was also, I think it was a major part of who I was...and it is now like a major part of my identity... I felt being a cancer survivor and having gone through this experience, cancer is just part of who I am now.”* (Interview 7; Testicular Cancer)

Some survivors were very proud of their cancer experience and chose to make their cancer history a prominent focus in their lives. As the following testicular cancer survivor explains:

*“Cancer defines me. ...my wife and I always do crazy things to raise awareness...I’m a testicular cancer survivor and so, it defines me because everybody knows me of that, and they don’t know me for doing anything else but that... I think it truly defines who I am...I celebrate it as a major part of who I am now.”* (Interview 9; Testicular Cancer)

**“Cancer doesn’t define me...”**. As opposed to those who very openly discussed how cancer was a major part of their current identity, others described it as playing only a small part in their lives and not something that defines them. As one breast cancer survivor described:

*“I do not believe that breast cancer has defined me, that but rather I’ve had the opportunity to redefine breast cancer. You know, it’s definitely a piece of my personal history, um, but it isn’t, you know, cancer only gets to be a part of who I am, it’s not all of who I am.”* (Interview 6; Breast Cancer)

For these survivors who felt that cancer was not a major part of their identity, they often stated that they wanted to be able to put their cancer experiences behind them and move forward. However, this was not always an easy task because others wanted to keep it in the forefront and would openly discuss it whether the survivor wanted to or not. The following quote from a breast cancer survivor highlights her experience when returning to work after treatment:

*“When I first went back to work it seemed that it was always part of the conversation with everybody. And after a while I was like ‘okay, enough, I don’t want to talk about it. Cancer is NOT who I am, please, I want to put it in my past!’”* (Interview 12; Breast Cancer)

Compared to those participants who considered cancer to be central to their lives and a major part of their identity moving forward post-treatment, many of these survivors who considered it a small part of their lives often noted that they hoped to leave cancer behind and not allow it to define their future.

*“You know, to me being a cancer survivor is as much as you know, uh, I’m an engineer...Like, it’s a small part of who I am, it doesn’t define me...and it’s not what’s going to define my future.”* (Interview 7; Breast Cancer)

Repeatedly during the interviews with these survivors, the statement ‘it’s just something that happened to me’ was emphasized. As one testicular cancer survivor states:

*“It [cancer] isn’t something I think about all the time at this point I guess. It’s kind of, you know, I go to see the oncologist every four months, but other than that, it’s not in my mind in the day to day. It’s just something that happened to me, not a big part of who I am on a day to day basis”* (Interview 6; Testicular Cancer)

In many cases, this lesser degree of illness centrality impacted their disclosure decisions. Because they wanted to emphasize the other parts of their identities and life experiences, they often chose not to discuss it with others and would attempt to change the topic to avoid centralizing their cancer history in conversations. As the following breast cancer survivor stated:

*“I don’t talk about it [cancer] at school, for a number of reasons... it’s one part of who I am, but it’s not the only part of who I am, I’m a lot of other things as well.”*

(Interview 8: Breast Cancer)

Overall, there were no observed gender differences between those who claimed cancer defines them and those who did not. Time since diagnosis did seem to be a factor, with more people early in their survivorship years situating cancer more central in their lives. However, this also may be because the newness of the experience created more situations where survivors had to make disclosure decisions, compared to those who had already returned to work or established relationships or careers post-cancer.

Neither those who had higher degrees of illness centrality nor those who felt that cancer played a lesser role in their self-identity saw it as a negative. In both cases, their choice of how central cancer was to their current identities was seen as a means of empowerment and coping. Most participants with higher levels of illness centrality were somewhat proud of what they had been through as a sign of strength. For those with lower degrees of illness centrality, it was empowering to be able to move forward past cancer and focus on other areas of their lives and their future without cancer. However, the participants in this study may not be an entirely representative sample due to the self-referral nature of recruitment and the fact that, like most research studies, those willing to participate may have been more well-adjusted and more likely to reflect on their cancer experiences.

## **Discussion**

The findings of this study highlight some of the important ways that young adult cancer survivors define and/or redefine their identities post-cancer and situate the cancer



experience into their lives after cancer. It also shows how illness centrality can play a key role in this process of identity (re)construction as survivors place different weights of importance on their cancer experiences as they move forward with their lives. Although most survivors admitted that cancer had an impact on their lives, the degree to which it was incorporated into their current self-identity varied. The centrality of the cancer experience ranged from playing a major role central to their lives to playing a minor role and not a self-defining factor. Those exhibiting more pronounced illness centrality were more likely to disclose their cancer histories to others, while those with less pronounced illness centrality were less likely to disclose.

Researchers have used the terms *identity reconciliation* (Zebrack, 2000), *self-transformation* (Carpenter, Brockopp, & Andrykowski, 1999), *reformulation of identity* (Fife, 1994), and *reintegration of the self* (Deimling, Bowman, & Wagner, 2007) to refer to this process of identity formation after a major life event such as a diagnosis of cancer. Although the terms may differ, there seems to be agreement that there is a degree of self-reflection and discovery that happens as individuals find ways to situate their illness experiences not just into their current selves, but also into their understandings of who they were and who they want to become in the future (Cantrell & Conte, 2009, Charmaz, 1995, Zebrack, 2000). As Charmaz (1991) points out, experiencing an illness such as cancer “may result in ill people’s self-concepts becoming tied to the past, present, or future. Thus, time plays a central, albeit hidden, role in shaping self-concept” (p. 229). There was slight variation in the degrees of illness centrality among participants in this study with those in the earlier survivorship years (<5 years post-diagnosis) exhibiting more pronounced illness centrality compared to those who were in the later years of

survivorship (>5 years post-diagnosis). Haidet, Kroll and Sharf (2006) also found in their study that illness centrality was highest at time of cancer diagnosis and decreased in intensity as they moved further from the diagnosis and treatment phases.

While many cancer survivors struggle to adjust to and cope with the impact of the disease and its treatment, studies show that they may also find opportunities for personal growth and improved wellbeing post-treatment (Deimling et al., 2007). Many individuals experience post-traumatic growth after cancer and actually have an improved quality of life (Folkman & Greer, 2000; Zebrack, Chesler, & Penn, 2007). As Park and colleagues (2009) point out, how individuals understand and identify with their cancer experience may be key factors to their adjustment to life post-cancer (Park et al., 2009). However, the experience of personal growth from the illness experience does not necessarily mean that survivors did not also experience psychological distress (Helgeson, 2011). The concept of meaning and how it relates to individuals' perceptions of the world around them is also an important contributing factor to their adaptation to illness. The meanings that individuals ascribe to their cancer experiences have the potential to influence the ways in which they cope with their illness and the after effects of the disease and treatment (Luker, Beaver, Lemster, & Owens, 1996; Park et al., 2009). This search for meaning is what allows cancer survivors to accept this illness experience as a formative event in their lives and find benefits even if the experience itself may include physical, psychological, and social challenges (Little et al., 2002).

In this study, many struggled with the loss of former identities and the fact that this new illness-related identity often took the forefront, whether self-imposed by the survivors themselves or conferred by others. Deimling and colleagues (2007) refer to this

as *identity salience hierarchy*, where identities that may have been central to an individual's self-concept diminish in importance in the face of an illness and are replaced by this illness-related identity. Survivors struggled most when they felt that others imposed this high level of salience to their cancer experience without recognizing and acknowledging the ways in which these individuals wanted to present themselves to others. Kelly and Millward (2004) differentiate between private identity (relating to self) and social identity (relating to others); however, they assert that there is considerable interplay between the two and that ultimately identity is always located in the social. Social identity relates to how an individual's identity is seen by others, but it is also shaped on a personal level by how the individual thinks that others see their identity, whether actual or perceived (Kelly & Millward, 2004). Through self-reflection and self-appraisal, this external perception of identity conferred on the individual by others may be incorporated into their overall self-identity (Little et al., 2002).

### **Conclusion**

Long-term survival after being diagnosed with cancer involves a process of negotiation as survivors attempt to situate their cancer experiences into the context of their current lives and try to make sense of their past, present and future selves. Based on the findings of this study, illness centrality is a major factor in defining an individual's concept of self-identity after cancer. Illness centrality may be particularly salient for young cancer survivors as they deal with the developmental task of identity formation associated with this stage of life while attempting to process and cope with the challenges of being diagnosed with a life-threatening or life-altering illness. Understanding the ways in which young adult cancer survivors situate their cancer experiences within their

current lives and (re)define their sense of self post-cancer may be key to understanding how they relate to others and the world around them after treatment. This may be helpful in finding new ways to support young cancer survivors as they transition from patient to survivor and attempt to (re)integrate into the social world, both personally and professionally.

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## **CHAPTER V**

### **General Discussion**

The focus of this chapter is a synthesis of the research findings presented in the previous chapters. Using a constructivist grounded theory approach, this study provides an in-depth look at the experiences of young adult cancer survivors, their motivations for self-disclosure, and the sense of identity that develops as they attempt to reintegrate back into the social world after the completion of cancer treatment. A better understanding of the experiences of young adult cancer survivors and how they communicate about their cancer history will be useful in the development of intervention strategies aimed at assisting them to better cope with challenges of self-disclosure and interpersonal relationships after cancer. The social impact of cancer on young adults is particularly salient at a stage of life when many important connections and relationships, both personally and professionally, are just being established (Robinson, Miedema, & Easley, 2014).

### **Summary of Previous Chapters**

The first chapter of this dissertation features an introduction to the research topic, an overview of the study design and a description of the thesis layout. Chapter 2 focuses on my methodological approach and the variety of ways in which I was able to acknowledge and incorporate my positionality as a young adult cancer survivor researching young adult cancer survivors into the research process. It features some of the questions, challenges, and opportunities that emerged throughout my doctoral research experience as I sought out ways to professionally situate myself within my research and become more mindful and self-aware as a researcher. This chapter concludes by stressing

the importance for researchers to examine where they are in relation to the area of interest in order to make meaningful linkages to the data that is generated and presented.

The findings in Chapter 3 highlight the intricacies of cancer history disclosure decisions as illustrated by the young breast and testicular cancer survivors in this study. Participants described both approach-focused (towards a perceived benefit) and avoidance-focused (avoiding a perceived risk) motivations for disclosure or non-disclosure which filter through a series of situational/contextual factors to determine the final disclosure decision (Chaudoir & Fisher, 2010). Overall, the participants in this study who expressed approach-focused motivations were more likely to disclose their cancer history than those expressing avoidance-focused motivations. Approach-focused motivations included desires for understanding, acceptance, to support/relate to others and to promote cancer awareness. Avoidance-focused motivations included fears of discrimination/stigmatization, unwanted attention, pity, privacy loss, and rejection. Situational/contextual factors described by the participants that often influenced the final disclosure decision included social/cultural context, relevance/timing, the person disclosing, the audience/confidant, and the time passed since diagnosis.

During the analysis of the interview data, self-identity and illness centrality emerged as major themes relating to how young adults situate themselves in relation to others and how they communicate with others about their cancer experiences. Chapter 4 highlights some of the ways in which young adult cancer survivors (re)construct, redefine, and/or embrace their identities post-cancer and how they situate their cancer experience within their overall self-concept. It also shows how illness centrality can play a key role in this process of identity (re)construction and highlights how cancer survivors

often place different weights of importance on their cancer experiences as they move forward with their lives.

### **Theoretical Model of the Disclosure Decision Process of Young Adult Cancer Survivors**

Throughout this research, I have used constructivist grounded theory (CGT) as a framework to guide all parts of this study including data collection, analysis and the subsequent synthesis of findings presented in this chapter. CGT is a systematic but flexible method for collecting and analysing data with the goal of constructing a theory of a phenomenon or process based on the interpretation of the data collected (Charmaz, 2006). “Theory is grounded when it emerges from and generates explanations of relationships and events that reflect the life experiences of those people and processes that the researcher is attempting to understand” (Lawrence & Tar, 2013, p. 31). Using a CGT approach, the resulting theory emphasizes understanding rather than explanation (Charmaz, 2006).

The following theoretical model (see Figure 5.1) was developed based on my interpretation of the data collected which depicts the interplay of factors involved in the cancer history disclosure decision process for young adult cancer survivors. Building upon the Motivations for Cancer History Disclosure Model (see Figure 3.1) presented in Chapter 3, this expanded model highlights the dynamic nature of the disclosure decision process and some of the overarching social goals/drivers (Belongingness, Normalcy, Acceptance, Support, Control, Identity) that feed into each disclosure decision. It also elaborates on the approach and avoidance motivations described by the participants in this study (see Chapter 3) by describing in further detail the possible positive and

negative outcomes which feed back into the social drivers/goals, influencing subsequent disclosure decisions (depicted as a feedback loop in the model). These outcomes become both a product of disclosure and a shaper of future disclosure decisions. As Chaudoir and Quinn (2010) have noted, disclosure decisions are not static and the experience of one disclosure decision can often set the course for subsequent disclosure experiences. For example, if survivors experience a negative reaction after disclosing their cancer history they may be reluctant to disclose in the future. This model demonstrates the complexity of this dynamic process and how disclosure decisions can change and vary over time based on a variety of situational/contextual factors and prior disclosure experiences.

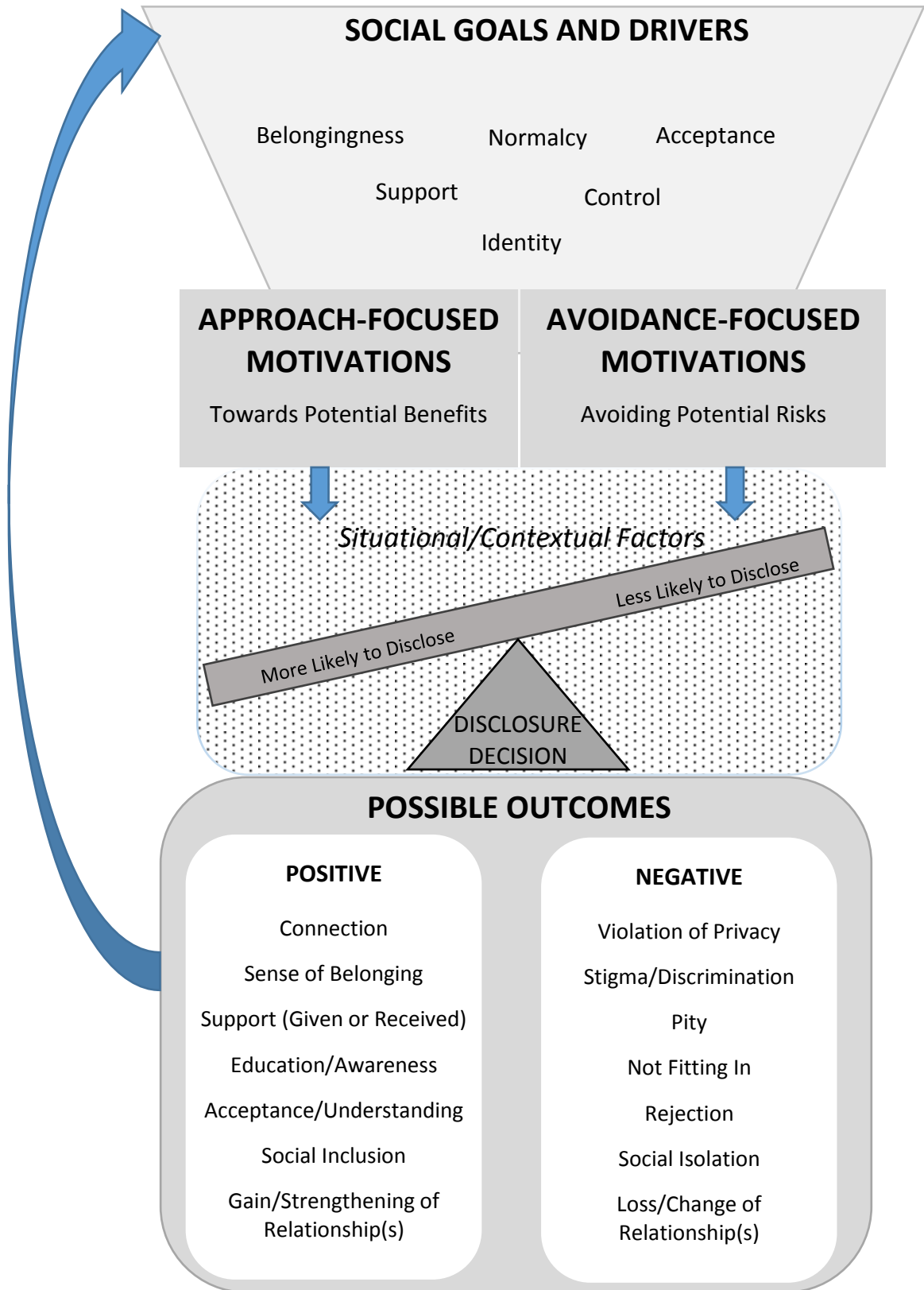


Figure 5.1. Disclosure decision model of young adult cancer survivors.

## **Social Goals/Drivers Influencing the Disclosure Decision Process**

Focusing specifically on the social impact of cancer, the theoretical model presented depicts a series of social goals and drivers that feed into the assessment of the potential benefits and risks of disclosing a cancer history. The terms *goals* and *drivers* are both used because many of these social constructs can act as either a goal, meaning something to hopefully achieve or attain, or they may already exist to some degree and act as a driver for action. For example, a young adult may be hoping to achieve the goal of a sense of normalcy or acceptance after cancer, therefore he or she may be motivated to disclose or withhold details about their cancer history, depending on the situation. On the other hand, as highlighted in Chapter 4, one's sense of identity after cancer may act as a driver for action when making a disclosure decision. In some cases, the social constructs can be both goals and drivers of action (e.g., belongingness, support, control) where they are constructs to achieve, strengthen and maintain as well as drivers for action. These social goals and drivers are not mutually exclusive. As an interpretive, constructivist study, these findings are based on the experiences described by the participants in this study, which means it does not exclude other interpretations or the possibility that other social goals/drivers and situational/contextual factors exist. The following section describes some of the social goals/drivers that influenced the disclosure decisions of the young adult cancer survivors in this study.

### **Belongingness**

As discussed in Chapter 3, many theorists posit that human beings are fundamentally driven by the need to belong (belongingness) to a social group by forming and maintaining lasting interpersonal relationships (Baumeister & Leary, 1995; Leary &

Cox, 2007; Walton, Cohen, Cwir, & Spencer, 2012). In this study, belongingness was one of the most prominent social goal/drivers which motivated these young adult cancer survivors to disclose or withhold information about their cancer history to others. This need to belong is particularly salient for young adult cancer survivors as their peers forge ahead with milestones typically associated with this stage of life such as establishing careers, marriage, and starting a family (Zebrack, 2011). The participants in this study described both approach motivations (Desire to Fit In; Desire for Understanding; Desire for Acceptance) and avoidance motivations (Fear of Rejection; Fear of Discrimination/Stigmatization) which are associated with the ultimate need and desire to belong.

The work of Leary and Cox (2007) supports this finding in their theory that much of human behaviour in general is motivated by the need for acceptance and fear of rejection. Researchers have shown that positive interpersonal relationships and a general sense of belonging can have a profound impact on well-being and meaningfulness in life (DeWall, Deckman, Pond, & Bonser, 2011; Lambert et al., 2013; Leary & Cox 2007). According to Baumeister & Leary (1995), “being accepted, included, or welcomed leads to a variety of positive emotions (e.g. happiness, elation, contentment, calm), whereas being rejected, excluded, or ignored leads to potent negative feelings (e.g. anxiety, depression, grief, jealousy, loneliness)” (p. 508). The social goal/driver of belongingness appears to be an important factor in motivating behaviour and influencing disclosure decisions among the young adult cancer survivors in this study.



## **Acceptance**

Closely related to belongingness is the social goal/driver acceptance. The need or desire to be accepted by others, and the subsequent show of acceptance, proved to be an overarching theme that factored into either disclosure or non-disclosure decisions. As highlighted in Chapter 3, some participants were motivated to disclose by the desire for acceptance, while others discussed a fear of discrimination/stigmatization (not being accepted) which was a motivation for non-disclosure. Young adults with cancer often lose confidence in disclosing due to their fear and uncertainty about the reaction of others and if they will be accepted (Zebrack, 2011). As Cordella and Poiani (2014) state, if individuals feel stigmatized, or fear stigmatization, they are at risk of becoming socially isolated which may lead to stress, anxiety, and depression. They posit that “the cancer patient may juggle the costs of stigma and the benefits and costs of disclosure which will change according to social circumstances and also the circumstances and needs of the individual” (Cordella & Poiani, 2014, p. 335). Further, the concept of acceptance was also discussed in relation to participants’ self-acceptance of their current reality, their *new normal*, and their newfound strengths and their limitations. In this context, acceptance relates to the concepts of identity and illness centrality as discussed in Chapter 4. How young people view themselves after cancer, and where they place their illness experience within their self-concept can impact how they feel about themselves and their level of acceptance of their current reality.

## **Normalcy**

Finding or defining some sense of normalcy after cancer is particularly challenging for young adults as their sense of normal may not have been defined due to

stage in life (Miedema, Hamilton, & Easley, 2007). Physical and cognitive changes caused by the illness can challenge central value and belief systems of the individual, and restoring or preserving some form of continuity or sense of normalcy after cancer can be a major task for survivors. Those who cannot achieve a sense of continuity in their lives or find ways to regain a sense of normalcy may experience social isolation and feel alienated from their friends and family (Little et al., 2002). Related to this social goal/driver, participants described the fear of unwanted attention and not fitting in as a prominent motivation for non-disclosure as part of their quest for normalcy. Others expressed a desire for understanding and acceptance as a motivation for disclosure in hopes that by normalizing their experience it would help them to reintegrate back into their social environment and redefine their sense of normalcy for themselves and for those around them. The need to belong and the need to control personal information about their cancer history relates to where survivors are in their quest for normalcy and acceptance of their situation.

### **Support (to Give and Receive)**

Social support is an important part of psychosocial care and quality of life for people diagnosed with cancer (Usta, 2012). In this study, many participants expressed a desire to give support to others diagnosed with cancer as well as a need to receive support from family, friends, and co-workers. Support was both a social goal and a driver of action for the participants. For some, the decision to disclose their cancer history was based on their hopes of receiving support or as a means of giving support to others, whereas in other cases it was because the participants felt supported and safe that they were motivated to then disclose their cancer history to their confidant. Individuals who

choose not to disclose their cancer history may miss out on opportunities to receive the support they need (Chaudoir & Fisher, 2010). As discussed in Chapter 3, young adult cancer survivors often experience feelings of social isolation and have difficulty initiating new relationships after treatment (Barnett et al., 2016; Zebrack & Isaacson, 2012). A lack of social support can be an issue for young adults diagnosed with cancer as their peers may not be able to relate to their experiences or recognize how to extend support to them as a friend (Warner et al., 2016).

### **Control**

Individuals diagnosed with cancer often feel a loss of control and power over their bodies and their lives. Many cancer survivors, particularly young adults, continue to struggle to regain a sense of control as they attempt to reintegrate back into their former lives after treatment is completed (Zebrack, 2011). In a study of adolescent and young adults with cancer, loss of control was described as being one of the biggest treatment-related challenges (Wicks & Mitchell, 2010). Self-disclosure is often a way for cancer survivors to regain some sense of control during a time when they may feel like they have so little due to cancer (Charmaz, 1991; Donovan-Kicken & Caughlin, 2011). For those who choose not to disclose, controlling communication about cancer preserves a sense of privacy which can help decrease feelings of vulnerability and increase feelings of autonomy and control (Margulis, 2003; Donovan-Kicken & Caughlin, 2011). Participants in this study described both approach and avoidance motivations for their disclosure decisions related to the social goal/driver of control. For some, the fear of pity and the fear of privacy loss were discussed as motivations for non-disclosure and their decision to withhold information about themselves was justified as a means of controlling the

information that is known to others about their cancer experiences. In other cases, participants felt that disclosing was a means of taking control before their cancer history was revealed or disclosed by other means. For those who were motivated to disclose their cancer history as a means of bringing awareness to their type of cancer or issues faced by young adults with cancer, it was often described as empowering and a way of taking the control away from the cancer. As discussed in Chapter 3, this is what Charmaz (1991) refers to as *strategic announcing*, which participants claimed helped to make them feel less vulnerable.

### **Identity**

Chapter 4 focuses specifically on the social goal/driver of identity and how illness centrality plays a big role in how cancer survivors see themselves and communicate with others about their cancer experiences. As Oyserman and colleagues state, “self and identity are predicted to influence what people are motivated to do, how they think and make sense of themselves and others, the actions they take, and their feelings and ability to control or regulate themselves” (Oyserman et al., 2011, p. 70). In this study, self-identity after cancer and illness centrality both influenced the likelihood of disclosure. For those that saw their cancer history as being a major part of their current identity and “a part of who they are now,” cancer history disclosure was more likely. On the other hand, those who viewed their cancer as less a part of their identity and described it as “just something that happened to me” were less likely to discuss their cancer history with others unless it was relevant or necessary. Identity development is a key developmental task and an important aspect of healthy growth for young adults (Zebrack, 2011). The way that individuals see themselves and situate their experiences in their lives directly

affects the way they see the world around them and their place within it. In turn, changes in the way these young adult cancer survivors see themselves in relation to the world after cancer, including their ability to carry out roles and responsibilities, may affect their overall sense of well-being and their interpersonal relationships.

### **Possible Positive and Negative Outcomes of Disclosure Decisions**

As illustrated in the theoretical model, the social drivers/goals described above feed into the approach or avoidance-focused motivations which are ultimately driven by the possible positive or negative outcomes of cancer history disclosure. Possible positive outcomes include (but are not limited to) feelings of connection and a sense of belonging; support (given and/or received); education and awareness of cancer issues and the young adult experience; social inclusion; acceptance and understanding from others; and the development or strengthening of relationship(s). Possible negative outcomes include (but are not limited to) violation of privacy; perceived or experienced stigma/discrimination; pity; social isolation and feelings of not fitting in with others; and a loss or change of relationship(s). In turn, these outcomes feed back into the overall social drivers/goals towards a sense of or quest for normalcy, belongingness, support, acceptance, identity, and control.

### **Finding Meaning after Cancer**

Central to the discussion of self-disclosure is the concept of meaning and how it relates to individuals' perceptions of the world around them, adaptation to illness, how it influences the concept of personal identity and how individuals relate to each other. It is the meaning which individuals construct about life events and social situations that enables them to organize the world around them and make sense of their own place

within that world (Fife, 2005; Mirowsky & Ross, 1986). The onset of a life-threatening illness such as cancer can have a deep-rooted impact on an individual's identity and perception of the future. According to Fife (2005), this can be "devastating and result in negative change, or its effects may be moderated by coping strategies that facilitate the continuing pursuit of current goals, or it may result in awareness of unrealized potential and re-focusing on the achievement of new possibilities (p.2132).

The meanings that individuals ascribe to their cancer experience have the potential to influence the ways in which they cope with and communicate about their illness and the after effects of the disease and treatment. Difficulties developing and maintaining social relationships can result in a decreased sense of meaning in life; and conversely the presence of positive social relationships with others is often associated with an increased sense of meaningfulness (Lambert et al., 2013). The social goals/drivers of belongingness, normalcy, control, acceptance, support, and identity are all intertwined with the way individuals make meaning from their environments and their experiences. Therefore, how individuals conceptualize and find meaning after cancer can impact how they feel about themselves and how they communicate with others. It is understandable then that the concept of meaning as a fundamental dimension of human life would play a major role in the individual's response to a traumatic event such as cancer, particularly for young adults who are already struggling within the transitional stage of life on their way to adulthood. Even if the experience of cancer creates many physical and psychosocial challenges, many cancer survivors find that the search for meaning after cancer helps them to accept the illness experience as a formative event in their lives and to find positive aspects and benefits (Little et al., 2002). This is often

referred to as *benefit finding* or post-traumatic growth and it raises the possibility that many cancer survivors can actually have an improved quality of life after cancer (Folkman & Greer, 2000; Wicks and Mitchell, 2010; Zebrack, Chesler, & Penn, 2007). Despite the many physical, psychological, and social challenges described by participants in this study, the majority were able to still find positive aspects of having cancer such as feeling stronger as a person, having a newfound perspective on life, and being better able to cope with and deal with other life stresses.

### **Implications of the Findings**

Gaining a better understanding of the cancer history disclosure decision process of young adult cancer survivors will help them to better adapt and socially reintegrate back into their pre-cancer lives after the completion of treatment. Understanding disclosure decisions and communication issues will also be beneficial to healthcare professionals in the development and provision of better support interventions and informational resources to help improve young adult cancer survivors' psychosocial well-being after cancer. Although healthcare professionals may be more actively involved in the care of young adults during the acute cancer treatment phase, it is still important to be aware and open to discussion about the social impact of cancer and the challenges of social reintegration after cancer to help support these young adults as they transition into the survivorship phase. As stated throughout this dissertation, young adults are a vulnerable population of cancer survivors as they struggle to deal with the physical, psychological, and social impact of cancer in conjunction with the many developmental tasks and milestones associated with this stage of life (Barnett et al., 2016; Miedema et al., 2006; Miedema et al., 2007; Zebrack, 2011). As more and more people are diagnosed

with cancer, communication issues become an important topic related to cancer patients and survivors of all ages. Historically, a cancer diagnosis was considered a death sentence and people rarely talked about it in public. Now, with the improvements in the treatment of cancer and early detection, more people are surviving a cancer diagnosis and the experience of survivorship has become a critical focus in the cancer care continuum.

### **Limitations and Future Research**

One of the biggest challenges when undertaking any research related to self-disclosure is that you must first ask participants to come forward and disclose their diagnosis as part of the recruitment strategy. Automatically the research situation is altered as only participants who have chosen to disclose in the first place end up being a part of the research study. This challenge is understandable and unavoidable; however, even though participants may have been more likely to disclose in general I feel that this research still captures the intricacies of the disclosure decision process. Not everyone discloses all of the time and these subtleties of what motivates individuals to disclose and not at any given moment became the central focus of this study.

Secondly, the sample for this study is somewhat homogenous (predominantly female, urban, and Caucasian). The results of this study may not be transferable to other ethnic groups who may have different social support systems and cancer experiences. Although purposive theoretical sampling was used to invite as heterogeneous a sample as was possible, sampling was constrained by the parameters of the self-referral nature of the recruitment strategy and it proved to be difficult to recruit testicular cancer survivors.

Lastly, I did not include palliative cases in the sample as they may have additional challenges related to their prognosis and health status. Future research on the experiences



of young adult cancer survivors and the social impact of cancer on interpersonal relationship development and maintenance is certainly warranted. It would be greatly beneficial to conduct a longitudinal study to see if and how disclosure decisions change among young adult cancer survivors over time as they get further from the diagnosis and acute treatment phases. An exploration of the experiences of males and females diagnosed with the same type of cancer would also be beneficial to see if gender has an influence on disclosure decisions. Future research could also be expanded to include all cancers in this age group to see if there are any notable differences of experiences and disclosure decisions based on cancer type.

### **Final Reflection**

As I near the end of this dissertation, I realize that this research was a big part of my own efforts to try and find meaning after my cancer experience. The topic was initially inspired by my personal experiences and struggles with self-disclosure, figuring out if, when, how and to whom I would disclose my cancer history. As I listened to my participants talk about their post-cancer identities and where they placed cancer in relation to their self-concept, I could relate to those who expressed that cancer is “just part of who I am now.” In some ways, researching cancer became my way of trying to regain a sense of control in my life over cancer. A small part of me felt driven by the need to learn as much as I could about cancer so that I would never be caught off guard and feel vulnerable to it again. But mostly, researching young adult cancer issues was my way of giving back and attempting to fill a very large gap in support that I experienced after treatment. Cancer is part of my normal now. I have learned to accept it as part of my life and have learned to cohabitate with the long-term effects of treatment. I have chosen

to use the experience as a stepping stone to propel me forward in life. It may not be the life I had envisioned before cancer, nonetheless, it is still moving forward. Reflecting on the interviews conducted with the participants in this study, I realize that everyone has their own way of coping and finding meaning after cancer. What works for one person, may not be what works for someone else. The same goes for self-disclosure; where one person may feel motivated to disclose their cancer history, another individual may not. Everyone is in charge of carving their own path towards socially reintegrating after cancer, and that path may not always go in a clear, straight line. As I write these last few paragraphs of this dissertation, I feel overwhelmed with a sense of satisfaction, no matter how many hurdles I had to jump over and no matter how long it took to get here. My hopes are that this research will contribute in some positive way to helping other young adults diagnosed with cancer get the support or insight they need; will help health care providers recognize and address the unique needs of this population; and that it will hopefully inspire future research related to communication issues and cancer.

### **Conclusion**

The goal of this study was to look at the cancer history disclosure patterns of young adult cancer survivors and the impact these decisions have had on their social interactions and overall experiences throughout their survivorship years. This research helps to fill a gap in research on young adult cancer experiences and it adds to the growing body of literature focusing on the topic of self-disclosure in the context of cancer. The theoretical model presented illustrates the complex and dynamic decision process involved as young adults decide whether to disclose or withhold information about their cancer history, as well as some of the social goal/drivers and the

situational/contextual factors that contribute to this process. This information will be beneficial for health care providers, support agencies, and researchers to gain a better understanding of the communication and interpersonal relationship issues faced by young cancer survivors in order to develop better support interventions and informational/educational resources to help this under-researched and vulnerable population.

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## **Appendix A: Participant Information and Consent Form**

Study Title: Disclosure Patterns of Young Adult Cancer Survivors and the Impact on Social Reintegration

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Thank you for your interest in this study. Before we can start the interview, you should first review this consent form. What follows is information about the study and a description of the study's procedures. If you choose to participate, you will be asked to provide oral consent at the beginning of the telephone interview. This consent form may contain words that you do not understand. Please ask me to explain any words or information that you do not clearly understand.

### **Introduction**

I am a graduate student at the University of New Brunswick and I would like invite you to take part in my research study on the experiences of young adult cancer survivors. Your participation in this study is completely voluntary and if you do decide to participate, you may withdraw from the study at any time. Your future healthcare will not be affected by whether or not you participate. The study is described below. This description tells you about the risks or discomfort which you might experience. Participating in the study might not benefit you, but I hope to learn things that will benefit others. You will be asked to provide oral consent after reviewing this consent form.

### **Purpose of the Study**

The purpose of this study is to explore the ways in which young adult cancer survivors cope with and communicate about their cancer diagnosis and how their cancer experiences have impacted their social relationships and social environments after treatment, both personally and professionally. Specifically, I will be interviewing 30 (15



female; 15 male) breast and testicular cancer survivors from across Canada over the telephone to discuss the impact cancer has had on their lives and the details about how, if, when and to whom they disclose information to others about their cancer diagnosis. Results from this study will be used to make recommendations for the design of support interventions to help young adults communicate about cancer and cope with issues that may arise as they attempt to reintegrate back into personal and professional life following cancer treatment.

### **Study Procedures**

If you agree to take part in this study, I will ask you to participate in a telephone interview that will last approximately one hour. Prior to the interview, we will discuss this consent form and I will answer any questions and address any concerns you may have. I will then ask you permission to record your oral consent to proceed if you are comfortable participating in this study. During the interview, I will ask you a number of demographic questions to provide me with some background information about you and your diagnosis. The interview questions are general in nature and ask you to discuss your experience with cancer and any issues you are now facing since completing cancer treatment, specifically in relation to your thoughts, feelings and experiences disclosing your cancer history and communicating about your cancer experience to your friends, family, co-workers and strangers. You will be given the option to consent to the interview being audio recorded. The interviews will be transcribed and then analyzed by me to look for common themes. No names or identifying information will be used in the reporting of the study results.

### **Who can participate in the study?**

You may participate in this study if you were diagnosed with breast or testicular cancer between the ages of 18 and 39 and it has been 1 to 10 years since your cancer diagnosis.

### **What you will be asked to do:**

You will be asked to

- 1) Read this consent form and give oral consent over the telephone
- 2) Participate in the interview

### **Possible Risks and Discomforts**

Participating in the study involves minimal risks. However, if at any time during or after the interview or survey, you feel upset or would like to talk to someone about the issues discussed, you can contact psychologists Dr. Rama Gupta-Rogers (English) at (506) 452-5287 or Dr. Carole Lamarche (French) (506) 452-5287 at the Dr. Everett Chalmers Regional Hospital in Fredericton, New Brunswick. If you would like to speak to one of the psychologists and you live outside of the Fredericton area, you may call my toll-free number 1-888-539-2272 and I will have a psychologist return your call. You may also contact me or my supervisors with any questions or concerns.

### **Possible Benefits**

There may or may not be direct benefits to you from participating in this study, however, we hope the information gained from this study will benefit other young adults who have been diagnosed with cancer.

### **Compensation / Reimbursement**

You will not be compensated for participating in this study.

### **Confidentiality & Anonymity**

This project has been reviewed by the University of New Brunswick (UNBF REB #2010-085) and Horizon Health Network (RS# 2010-1503) Research Ethics Boards.

Information gathered in this research study may be published or presented in public forums; however your name and other identifying information will never be used or revealed. The interview files will be coded and only I will be aware of your identity. Nobody but me will have access to the raw data. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. For audit and quality control purposes the Research Ethics Board may request access to the raw data. The digital files and the raw data (transcripts of the audio-recorded interviews) will be stored as computer files. These computers are password accessible only by the researchers and the offices are housed in a hospital setting in secure offices. After the study is completed, the data will be stored for a period of 7 years after which all data will be appropriately deleted or destroyed.

### **Questions**

If you have any questions about this study, you may contact me by leaving a message by phone at 1-888-539-2272 (toll free) or by e-mail [julie.easley@unb.ca](mailto:julie.easley@unb.ca).

### **Problems or Concerns**

If you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, you may contact Dr. Linda Eyre, Assistant Dean, School of Graduate Studies, Interdisciplinary Studies, University of New Brunswick, Fredericton, NB by phone (506) 453-5161 or by e-mail at [leyre@unb.ca](mailto:leyre@unb.ca)

### **Voluntary Participation/Withdrawal from the Study:**

Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time. You may refuse to answer any questions that you do not feel comfortable answering. If I feel that it is in your best interest for you to withdraw from the study, I will remove you without your consent.

### **Audio-taping of the Interview:**

I would like to have your consent to audio-tape the interview. I will ask you if you consent to the audio taping of the interview before beginning the telephone interview. You may ask for the recording device to be turned off at any point.

Consent given for audio taping?    Yes            No            Interviewer Initials: \_\_\_\_\_

**Unidentifiable Quotes:**

I would like to be able to use unidentifiable excerpts of your interview to support the findings of the project. For publication purposes, all identifying information will be removed from the qualitative data. I will ask you if you consent to the use of unidentifiable excerpts before beginning the telephone interview.

Consent given for use of interview quotes? Yes No Interviewer Initials: \_\_\_\_\_

**Statement of Consent:**

By giving oral consent, you understand and agree with the following statements:

- You have received this consent form by fax, mail or e-mail and have had an opportunity to have your questions answered in a language that you understand. The risks and benefits have been explained to you and you understand that your participation in this study is voluntary.
- You understand that you may choose to refuse to answer any questions and you may withdraw from the study at any time without consequence. You freely agree to participate in this research study.
- You understand that information regarding your personal identity will be kept confidential and that within limits of the law, confidentiality will be guaranteed.
- You understand that you have not waived any of the legal rights that you have as a participant in a research study.

**Signature by Interviewer for Oral Consent**

Printed Name of Interviewer	Signature of Interviewer	Date

**Study Summary**

If you would like to receive a summary of the study results, please provide your name and address and/or e-mail so we can forward the summary to you.

Name: \_\_\_\_\_

Address: \_\_\_\_\_

E-mail: \_\_\_\_\_

Phone: \_\_\_\_\_

## Appendix B: Interview Guide

Thank you for participating in this research. As you know, you do not have to answer any questions and there are no right and wrong answers. I would like to ask you some question about your cancer diagnosis and your experiences since completing treatment.

- 1) Can you tell me a little bit about yourself? (hobbies, education, family, etc.)
- 2) Could you please tell me a little bit about when you were diagnosed with cancer?  
Probes: - age of diagnosis, what was going on your life at the time? type of treatment, feelings about diagnosis/treatment
- 3) What happened after your cancer treatment was completed?  
Probes: Physical Issues? (physical limitations, treatment-related issues)  
Psychological Issues? (i.e. coping issues, fear of recurrence, comparison to peers)  
Financial Issues? (health insurance, debt)  
Work, Education, Career Plans/Interruptions?
- 6) Since your cancer treatment, have issues around your sexuality and sexual experience changed for you?  
Probes: fertility, potency, relationships, body image/weight, how you feel about your body?
- 7) How have your experiences been with relationships?  
Probes: Family? Friends? Intimate Relationships? New acquaintances?
- 8) How do you feel about telling people about your cancer diagnosis?
  - o Who do you tell?
  - o Who don't you feel comfortable telling and why?
  - o How do you tell people?
- 9) Can you give me an example of a time when you had to disclose your cancer diagnosis to a male friend? Female friend? New acquaintance? Co-worker/Employer?
- 10) How do you feel your decision to tell or not to tell about your cancer diagnosis and feelings about your experiences have impacted your relationships with other people?  
Probes: family, friends, co-workers, strangers, new acquaintances, partner
- 11) How has cancer affected how you feel about yourself? What impact has cancer had on your life and overall well-being so far?
  - a. Personally? Professionally? Sexually? Compared to others (i.e. peers)?
- 12) Do you think you would feel differently about your situation if you were diagnosed with a different kind of cancer?

- 13) If you were to compare the “you” before cancer and the “you” after cancer, what would be different? Do you feel cancer has changed you in any way?
- 14) Do you feel that there are extra challenges because you are young?
- 15) Is there anything else you would like to add?

## Appendix C: Socio-demographic Questions

Study Title: Disclosure Patterns of Young Adult Cancer Survivors and the Impact on Social Reintegration

Participant I.D.: \_\_\_\_\_ Date: \_\_\_\_\_

1. Current Age: \_\_\_\_\_ Age at time of diagnosis: \_\_\_\_\_

2a. Type of Cancer: \_\_\_\_\_ Stage: \_\_\_\_\_

2b. Treatment: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

3. Province: \_\_\_\_\_

4. Do you live in an urban or rural community? (Urban = 10,000 people or more)  
1. Urban      2. Rural

5. Current Marital Status

1. Single
2. Married
3. Divorced
4. Separated
5. Widowed
6. Common law relationship

6a. Do you have any children?      Yes                      No

6b. If yes, how many and what age? \_\_\_\_\_

7. With which group do you identify the most?

1. Black (e.g., African, Caribbean etc.)
2. South Asian (e.g., Indian, Pakistani etc.)
3. East Asian (e.g., Chinese, Japanese, Korean etc.)
4. Southeast Asian (e.g., Thai, Filipino, Vietnamese etc.)
5. West Asian (e.g., Arabian, Iranian etc.)
6. South or Central American
7. Aboriginal
8. Caucasian/White
9. Other: \_\_\_\_\_

8. What is your highest level of education?

1. Finished primary or elementary school

2. Finished junior high school or middle school
3. Finished high school
4. Finished community college
5. Finished undergraduate degree at university
6. Finished a graduate degree at university

**9. Are you currently in school?**

1. No, not in school
2. No, on sick leave from school
2. Part-time
3. Full-time
4. Enrolled in a class

**10. What type of school program are you in?**

1. Undergraduate (Bachelors)
2. Graduate (Masters/PhD)
3. Community College
4. High School/ GED equivalent
5. Not in school

**11. What is your current employment status?**

1. Unemployed, looking for work
2. Unemployed, not looking for work
3. Full-time
4. Part-time
5. Casual/Self-employed
6. On paid sick leave
7. On unpaid sick leave (plan to return to previous job)
5. On Social/Government Assistance
6. Student, not in the workforce

**12. What is your occupation?** \_\_\_\_\_

**13. What do you estimate your current annual income to be?**

1. Less than \$20,000
2. Between \$20,001 and \$30,000
3. Between \$30,001 and \$40,000
4. Between \$40,001 and \$50,000
5. Between \$50,001 and \$60,000
6. Between \$60,001 and \$70,000
7. Between \$70,001 and \$80,000
8. \$80,001 or over
9. Does not wish to answer

**14. Do you have private health insurance? (e.g. Blue Cross)**

1. No
2. Yes

## Appendix D: Participant Profile

Study sample characteristic	<i>n</i>	%
Type of cancer (sex)		
Breast (female)	16	57.1
Testicular (male)	12	42.9
Stage of cancer		
Stage 1	6	21.4
Stage 2	15	53.6
Stage 3	6	21.4
Does not know	1	3.6
Years since diagnosis		
1-5 years	18	64.3
6 years and over	10	35.7
Region		
Western Canada (BC, AB, SK, MB)	11	39.3
Central Canada (ON, QC)	7	25.0
Eastern Canada (NB, NS, PE, NL)	10	35.7
Urban/rural		
Urban	21	75.0
Rural	7	25.0
Marital status		
Single	9	32.1



Married	11	39.3
Divorced	2	7.1
Separated	1	3.6
Common-law	5	17.9
Highest level of education		
High school diploma	7	25.0
Community college diploma	4	14.3
Undergraduate degree	12	42.9
Graduate degree	5	17.9
Employment status		
Unemployed	2	7.1
Full-time	12	42.9
Part-time	5	17.9
Self-employed	1	3.6
Student	7	25.0
On disability	1	3.6
Annual Income		
Less than \$20,000	8	28.6
\$20,001- \$40,000	11	39.3
\$40,001 - \$60,000	3	10.7
\$60,001 - \$80,000	3	10.7
More than \$80,001	3	10.7

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*Note.*  $N = 28$ . Mean age at diagnosis = 29(range = 19-26;  $SD$  5.11). Mean age at time of interview = 34 (Range 21-52;  $SD$  6.98).

## Curriculum Vitae

**Candidate's full name:** Julie Easley

**Universities attended:** Bachelor of Arts (Honours), Dalhousie University, 1997

Master of Arts, University of New Brunswick, 2006

University of New Brunswick, 2006–present

### **Publications:**

Easley, J., Miedema, B., Carroll, J. C., Manca, D. P., O'Brien, M. A., Webster, F. . .

Grunfeld, E. (In Press). The role of family physicians in cancer care: Perspectives of primary and specialty care providers. *Current Oncology*.

Easley, J., Miedema, B., Carroll, J. C., O'Brien, M. A., Manca, D. P., & Grunfeld, E.

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Easley, J., Miedema, B., Carroll, J. C., Manca, D. P., O'Brien, M. A., Webster, F., &

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Miedema, B., Easley, J., Thompson, A., Bovin, A., Aubrey-Bassler, K., Katz, A., ...

Wodchis, W. (2016). Access to primary care: Do new and traditional models of primary care differ? The Canadian QUALICOPC Study. *Canadian Family Physician*, 62(1), 54-61.

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- Easley, J., Miedema, B., & Robinson, L. (2013). "It's the 'good' cancer, so who cares?" Perceived lack of support among young thyroid cancer survivors. *Oncology Nursing Forum*. 2013; 40(6): 596-600
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- Easley, J. & Miedema, B. (2012). Rehabilitation after breast cancer: Recommendations from young survivors. *Rehabilitation Nursing*. 37(4), 163-169. Selected for Continuing Medical Education Credits.
- Miedema, B. & Easley, J. (2012). Barriers to rehabilitative care for young breast cancer survivors: A qualitative understanding. *Journal of Supportive Cancer Care*. 20(6), 1193-1201.
- Wilson-Forsberg, S. & Easley, J. (2011). Ethical potholes along the roads of rural research: Three potential concerns when embarking on research involving rural populations. In Kulig, J.C. & Williams, A. *Rural Health: A Canadian Perspective*. Vancouver: UBC Press.

- Hamilton, R., Miedema, B., MacIntyre, L. & Easley, J. (2011). Enhancing breast cancer survivors coping skills using a positive self-talk intervention: Lessons from a community based group delivery model. *Current Oncology*, 18(2), E46-E53.
- Miedema, B., Hamilton, R., Fortin P., Easley, J. & Mathews, M. (2010). "You can only take so much, and it took everything out of me:" Coping strategies of parents of children with cancer. *Palliative and Supportive Care*, 8(2), 197-206.
- Bottorff, J., McKeown, S., Carey, J., Haines, R., Okoli, C., Johnson, K., Easley, J...  
Ptolemy, E. (2010). Young women's responses to smoking and breast cancer risk information. *Health Education Research*, 25(4), 668-677.
- Miedema, B., Hamilton, R., Fortin, P., Easley, J., & Tatemichi, S. (2009). The challenges and rewards of rural family practice in New Brunswick, Canada: Lessons for retention. *Rural and Remote Health*, 9, 1141. Retrieved from <http://www.rrh.org.au/articles/showarticlenew.asp?ArticleID=1141>
- Miedema, B., Easley, J., Hamilton, R., Fortin, P. & Tatemichi, S. (2009) Disrespect, harassment and abuse: All in a day's work for family physicians. *Canadian Family Physician*, 55(3), 279-285.
- Miedema, B., Easley, J., Hamilton, R., Fortin, P. & Tatemichi, S. (2009) Crossing boundaries: Family physicians' struggles to establish boundaries to protect private lives. *Canadian Family Physician*, 55(3), 286-287.
- Miedema, B., Easley, J., Fortin, P., Hamilton, R., & Mathews, M. (2008). The economic impact on families when a child is diagnosed with cancer. *Current Oncology*, 15(4), 8-13.

Miedema, B., Hamilton, R. & Easley, J. (2008) Climbing the walls: Structural barriers to accessing primary care for refugee newcomers in Canada (Commentary). *Canadian Family Physician*, 54, 335-336.

Miedema, B., Hamilton, R. & Easley, J. (2007). From “invincibility” to “normalcy”: Coping strategies of young adults during the cancer journey. *Palliative and Supportive Care*, 5(1), 41-49.

Miedema, B., Easley, J., & Hamilton, R. (2006). Young adults’ experiences with cancer: comments from patients and survivors. *Canadian Family Physician*, 52(11), 1446-1447.

#### **Conference Presentations:**

Easley, J., Miedema, B., Carroll, J., O’Brien, M.A., Manca, D., Webster, F...Grunfeld, E. (2016, May). *How can we improve the coordination and overall experience of cancer care for breast and colorectal cancer patients? Qualitative results from the CanIMPACT study.* Paper presented at the Canadian Association of Psychosocial Oncology Conference, Halifax, NS.

Easley, J., Miedema, B., Carroll, J., O’Brien, M.A., Manca, D., Webster, F...Grunfeld, E. (2016, April). *The role of family physicians in cancer care: Perspectives of primary and specialty care providers.* Paper presented at The Cancer and Primary Care Research International Network (Ca-PRI) Conference, Boston, MA.

Miedema, B. & Easley, J. (2016, March). *CanIMPACT: Canadian Team to Improve Community-based Cancer Care along the Continuum: Qualitative component.* CanIMPACT Consultative workshop, Toronto, ON.

Anisimowicz, Y., Miedema, B., Easley, J. & Bowes, A. (2016, March). *New Brunswick Family Physicians: Factors influencing family medicine resident retention and newly graduated family physicians' first practice location*. Interprofessional Health Research Day, Saint John, NB.

Easley, J. & Miedema, B. (2016, March) *CanIMPACT: The Coordination of Cancer Care and the Importance of Communication Between Primary and Specialty Care Providers*. Poster presented at the Interprofessional Health Research Day, Saint John, NB.

Easley, J. & Miedema, B. (2015, November) *CanIMPACT: The Coordination of Cancer Care and the Importance of Communication*. Poster presented at the New Brunswick Health Research Foundation Conference, Fredericton, NB.

Miedema, B., Easley, J., Carroll, J., O'Brien, M.A., Manca, D., Webster, F... Grunfeld, E. (2015, June). *CanIMPACT Qualitative Data: The Importance of Communication in Cancer Care*. E-Poster presented at The Cancer and Primary Care Research International Network (Ca-PRI) Conference, Aarhus, Denmark.

Miedema, B., Easley, J. & Robinson, L. (2014, June). *Cancer in young adults: Challenges of intimacy during survivorship*. Paper presented at The Cancer and Primary Care Research International Network (Ca-PRI) Conference, Winnipeg, MB.

Miedema, B., Easley, J., Grunfeld, E. O'Brien, M.A., Manca, D., Webster, F... Lofters, A. (2014, June). *Canadian Team to Improve Community-Based Cancer Care along the Continuum (CanIMPACT) - Qualitative Component*. Poster presented at The

Cancer and Primary Care Research International Network (Ca-PRI) Conference,  
Winnipeg, MB.

Miedema, B., Easley, J., Hamilton, R., Reading, S. & Morrison, K. (2013, November).

*“Truthfully It Was Boring:” Reasons Why Obese Patients Drop Out of a Free Exercise and Nutrition Program.* Poster presented at the North American Primary Care Research Group, Ottawa, ON.

Morrison, K., Miedema, B., Reading, S., Hamilton, R. & Easley, J. (2013, November).

*Reasons why self-referred obese participants withdrew from a free lifestyle intervention program delivered by highly skilled professionals.* Poster presented at the New Brunswick Health Research Foundation Conference, Saint John, NB.

Miedema, B., Easley, J. & Robinson, L. (2013, April). *The Impact of Geography on the Experiences of Young Adult Cancer Survivors.* Paper presented at The Cancer and Primary Care Research International Network (Ca-PRI) Conference, Cambridge, UK.

Miedema, B., Reading, S., Hamilton, R., Easley, J., Morrison, K. & McLean. (2013, April). *Health Eating, Active Living for Tomorrow’s Health (HEALTH) intervention for the management of adult obesity: Did the intervention work?* Paper presented at the New Brunswick College of Family Physicians Annual Scientific Assembly, Caraquet, NB.

Miedema, B., Easley, J. & Robinson, L. (2012, November). *Does Geography Impact the Experiences of Young Adult Cancer Survivors? A Qualitative Comparison.* Poster presented at the Pre-conference Research Day at the Family Medicine Forum, Toronto, ON.

- Morrison, K, Miedema, B. Reading, S., Hamilton, R. & Easley, J. (2012, November). *A Participant Profile at Intake into the Healthy Eating, Active Living for Tomorrow's Health (HEALTH) Study for Management of Adult Obesity*. Poster presented at the New Brunswick Health Research Conference, Fredericton, NB.
- Easley, J. (2012, June). *Reflecting on Reflexivity: The problems, practicalities, and possibilities of recognizing and incorporating the researcher perspective throughout the research process*. Keynote address at the Innovations in Qualitative Research Conference, Saskatoon, SK.
- Miedema, B., Easley, J. & Robinson, L. (2012, May). *The Need for a New Model of Young Adult Cancer Follow-up Care in Canada*. Poster presented at the Applied Research in Cancer Control Conference, Montreal, May 28, 2012
- Easley, J., Miedema, B. & Robinson, L. (2011, November). *A New Model of Young Adult Cancer Follow-up Care in Canada*. Poster presented at the New Brunswick Health Research Foundation Conference, Moncton, NB.
- Hamilton, R., Thomas-MacLean, R. Quinlan, E. & Easley, J. (2011, May). *Creativity and activity: Developing supports for women experiencing disability after breast cancer*. Symposium presented at the Canadian Association of Psychosocial Oncology Conference, Toronto, ON.
- Easley, J. & Miedema, B. (2011, March). *Rehabilitation after Breast Cancer: Recommendations from Young Survivors*. Paper presented at the Interprofessional Health Research Day, Saint John, NB.



Easley, J. & Miedema B. (2010, June). *Identifying barriers to Rehabilitative Care for Young Breast Cancer Survivors in Atlantic Canada: A Qualitative Approach.*

Paper presented at the Dr. Donald MacLellan Research Day, Moncton, NB.

Easley, J. & Miedema, B. (2010, May). *The role of family physicians in the rehabilitative process of young women with breast cancer in Atlantic Canada.* Poster presented at The Cancer and Primary Care Research International Network (Ca-PRI)

Conference, Toronto, ON.

Easley, J. & Miedema, B. (2010, May). *Barriers to physical and psychosocial rehabilitative care for young breast cancer survivors in Atlantic Canada.* Paper presented at the International Psycho-Oncology Association (IPOS). *Psycho-Oncology* 19 (suppl. 2) -1-313, Quebec City, QC.

Hamilton, R., Easley, J., Miedema, B. & MacIntyre, L. (2010, May). *The impact of a Positive Self-Talk Intervention on Breast Cancer Survivors Coping Skills and Psychological Well-Being – Workshop Demonstration and Discussion of Results.*

Paper presented at the International Psycho-Oncology Association (IPOS). *Psycho-Oncology* 19 (suppl. 2) -1-313, Quebec City, QC.

Easley, J., Miedema, B. & Tschirhart, N. (2009, November). *Barriers to rehabilitative care for young breast cancer survivors in Atlantic Canada,* Poster presented at the North American Primary Care Research Group Conference, Montreal, QC.

Hamilton, R., Easley, J., MacIntyre, L. & Miedema, B. (2009, November). *The Role of Positive Self-talk in Enhancing Cancer Survivors' Coping Skills,* Poster presented at the North American Primary Care Research Group Conference, Montreal, QC.

Bottorff, J., Haines, R., McKeown, S., Carey, J., Okoli, C., Johnson, K., Easley,

J...Ptolemy, E. (2009, November). *Smoking and breast cancer risk information: What young women have to say*. Paper presented at the 6<sup>th</sup> National Conference on tobacco or Health, Montreal, QC.

Bottorff, J., Haines, R., McKeown, S., Carey, J., Okoli, C., Johnson, K., Easley,

J...Ptolemy, E. (2009, October). *Raising awareness of new risk information about premenopausal breast cancer: Young women's views*. Paper presented at the 21<sup>st</sup> Annual Canadian Association of Nurses in Oncology Conference, Montreal, QC.

Miedema, B., Easley, J., Hamilton, R., Tschirhart, N. & MacIntyre, L. (2009, May).

*Breast cancer research at the Dalhousie University Family Medicine Teaching Unit*. Paper presented at the New Brunswick Breast Cancer Network Symposium, Fredericton, NB.

Miedema, B., Easley, J. Hamilton, R. & Fortin, P. (2008, June). *Disrespect, harassment*

*and abuse: All in a day's work for family physicians*. Paper presented at the 43<sup>rd</sup> Conjoint Scientific Assembly as part of the Medical Literary Award, Charlottetown, PE.

Easley, J. (2008, May). *Vocational rehabilitation needs of young adult cancer survivors*.

Paper presented at the Canadian Association of Psychosocial Oncology Conference, Halifax, NS.

Park, A., Mathews, M., Miedema, B., Fortin, P., Easley, J. Hamilton, R...Ringuette, J.

(2008, May). *What is the impact of a delayed diagnosis?* Paper presented at the Canadian Association of Psychosocial Oncology Conference, Halifax, NS.

- Wickham, S., Mathews, M., Miedema, B., Fortin, P., Easley, J. Hamilton, R...Ringuette, J. (2008, May). *The impact of a child's cancer diagnosis on his/her siblings*. Paper presented at the Canadian Association of Psychosocial Oncology Conference, Halifax, NS.
- Miedema, B., Fortin, P., Easley, J. & Hamilton, R. (2008, May). *The Challenges and Rewards of conducting a Bilingual Research Project*. Poster presented at the Canadian Association of Psychosocial Oncology Conference, Halifax, NS.
- Bottorff, J., Johnson, K., Brazier, A., Easley, J., Baillie, L., Ferrence, R...Carey, J. (2008, April). *Increasing awareness of smoking and breast cancer – where are we at?* Paper presented at the Reasons for Hope Conference, Winnipeg, MB.
- Miedema, B., Tatemichi, S., Easley, J., Hamilton, R. & Fortin, P. (2007, October). *Crossing boundaries: The struggle to establish professional and private boundaries for family physicians*. Paper presented at the Family Medicine Forum Research Day, Winnipeg, MB.
- Miedema, B., Hamilton, R. & Easley, J. (2007, May). *Barriers to Accessing Health Care for Newcomers in New Brunswick: A Qualitative Analysis*. Paper presented at the Canadian Sociological Association 42<sup>nd</sup> annual meeting during the Congress of Humanities and Social Sciences, Saskatoon, SK.
- Easley, J., Miedema, B., Hamilton, R. & Fortin P. (2007, May). *The Economic Burden of Childhood Cancer on Families in New Brunswick*. Paper presented at the Canadian Association of Psychosocial Oncology Conference, Winnipeg, MB.

- Hamilton, R., Miedema, B., Easley, J. & Fortin, P. (2007, May). *Psychosocial Adjustment of Children Surviving Cancer*. Paper presented at the Canadian Association of Psychosocial Oncology Conference, Winnipeg, MB.
- Easley, J. (2007, April). *Ethical 'potholes' along the back roads of rural research*. Paper presented at the 3<sup>rd</sup> Annual Symposium on Ethics in Research, Fredericton, NB.
- Miedema, B., Easley, J. & Hamilton, R. (2006, October). *Delayed Cancer Diagnosis in Young Adults*. Paper presented at the North American Primary Care Research Group Conference, Tucson, AZ.
- Easley, J. (2006, May). *Experiences of young adult cancer survivors: Financial Challenges*. Paper presented at the Canadian Association of Psychosocial Oncology Conference, Montreal, QC.
- Easley, J. (2005, October). *From survivor to caregiver: Lessons from the flip side*. Invited presentation at the Clinical Day in Oncology; Support for Patients and their Families, Fredericton, NB.
- Easley, J. (2004, June). *Sociocultural factors of cancer: Risk, representation and experience*. Paper presented at the 2<sup>nd</sup> Annual Social Sciences in Health Colloquium - Interdisciplinary Perspectives on Health and Health Care: Social Science and Humanities Approaches, Fredericton, NB.
- Easley, J. (2003, February). *Smoking decisions: Tobacco use and cancer awareness of adolescent girls in New Brunswick*. Poster presentation at UNB's 11<sup>th</sup> Annual Conference on Student Research, Fredericton, NB.
- Easley, J. & Mitra, K. (2002, October). *Young women's health awareness: Perceptions of risk factors for cervical cancer among high school and university students in New*

*Brunswick*. Poster presented at the Canadian Association of Physical Anthropology Conference, Ottawa, ON.

Easley, J. & Mitra, K. (2002, October). *Smoking behavior and cancer awareness of adolescent girls in New Brunswick*. Paper presented at UNB's 1<sup>st</sup> Annual Social Sciences in Health Colloquium, Fredericton, NB.