

EMERGING ADULT CANCER: PARENTS' PSYCHOSOCIAL CHALLENGES

by

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Abstract

Previous research on how pediatric cancer affects the parent has found that parents experience decreased sense of personal functioning, mental health, and physical health, and negative changes in close relationships. To date, no research has shown how parents are affected when their emerging adult child (i.e. children between the ages of 18 to 25) experiences cancer. Considering the emphasis on newfound independence and self-focus in emerging adulthood, parents are expected to face unique psychosocial challenges when their emerging adult child has cancer. The purpose of this qualitative collective case study is to understand those challenges. Data were analyzed by thematic analysis. Themes emerged around parents not being heard or understood, independence of the child, changes in work and social life, and support. This study will inform further research and act as an advocacy tool for support and interventions specific to parents of emerging adult children with cancer.

List of Abbreviations

AYA: Adolescent and Young Adulthood

EA: Emerging Adulthood

PTG: Posttraumatic Growth

PTSD: Post-Traumatic Stress Disorder

WHO: World Health Organization

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Chapter 1: Introduction

Previous studies on AYA (Adolescent and Young Adult) cancer, including those on both the patient and the parents, have given us a fair amount of information about cancer during the chronological age range of AYA. As emerging adulthood is an in-between stage and based on a developmental stage, it is important to understand the effects on parents during this stage. A general term for over 1000 diseases, cancer is defined by abnormal cells uncontrollably dividing and spreading throughout the body by way of the blood and lymph systems (World Health Organization [WHO], 2015a). Two of every five Canadians will develop cancer in their lifetimes, and one in four will die of their disease (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2015). Within oncology, patients are generally divided into three groupings: child (pediatric), adolescent and young adult (AYA), and adult. Given its pervasive nature, cancer can affect all aspects of one's life, such as social interactions, education/employment attainment and continuity, and intimate relationships (Adler & Page, 2008), as well as the patient's family. Families have been found to experience mental health issues and stress-related physical symptoms, as well as persistent fears and existential/spiritual questions (Osse et al., 2006). Family members and, in particular, parents of the patient, can take on the caregiving role, and be faced with carrying out multiple roles simultaneously, leading to increased feelings of strain and negative affect (Kim et al., 2006).

The Canadian Cancer Society defines children as those between 0 to 14 years, AYA as those between 15 to 29 years, and adults as anyone 30 years of age and above (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2015). These

definitions differentiate each life stage by chronological age, rather than development life phase. Development stage theory posits that life stages are transitional periods marked by specific experiences (Erikson, 1950; 1968). As such, developmental stages rather than chronological age spans, may enhance understanding of the cancer experience, specifically the effects on parents. Encountering cancer in one's child may affect a parent differently depending on whether the child is a pediatric patient, adolescent, emerging adult, young adult, or adult. Each life phase is characterized by specific experiences and challenges which can affect how the parent processes the cancer diagnosis, treatment, and resulting outcome. A relatively new developmental life stage, emerging adulthood, has been proposed by Arnett (2000) who proposes that the stage between the ages of 18 to 25 is distinctive from other stages in its demographics, subjective perceptions, and identity explorations. Given these distinctions, it is possible that cancer can affect both the emerging adult (EA) and his/her parent differently during this development life phase than it would during other life phases, such as childhood, adolescence, and adulthood.

Cancer in AYA

There is an increasing interest among researchers on the topic of AYA cancer. In Canada, the special topic of the 2009 edition of *Canadian Cancer Statistics* was "Cancer in Adolescents and Young Adults" (Canadian Cancer Society's Steering Committee, 2009), and the Canadian Task Force on Adolescents and Young Adults with Cancer (AYA Task Force) was created to research treatment and survivorship issues of AYA cancer patients (Canadian Partnership Against Cancer, 2011). Globally, studies have recently been published regarding issues specific to AYA cancer, such as psychological health, fertility, and survivorship (Geue et al., 2014; Sender, 2013, Zebrack et al., 2014).

There is also a journal dedicated to this topic, the Journal of Adolescent and Young Adult Oncology (JAYAO). Research on the effects of cancer on the parents of the AYA patients has been more limited. The work by Anne Grinyer has been an exception, as she has studied the impact of caregiving for an AYA child with cancer on mothers' health (2006), as well as the effects of a bereavement group for parents who have lost a child to cancer (2012). In addition, Carey, McHard, Sanson-Fisher, and Shakeshaft (2012) created an unmet needs survey for parents and caregivers of AYA cancer patients.

Approximately 1.5% of new cancer cases in Canada are diagnosed in AYA aged 15 to 29 years of age (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2015). Within this age group, the most commonly diagnosed cancers are thyroid, testicular, Hodgkin lymphoma, and melanoma (Canadian Cancer Society's Advisory Committee on Cancer Statistics). Of all cancer-related deaths in Canada, less than 0.5% are AYAs, with an average of 290 people in Canada between the ages of 15 and 29 dying from cancer each year. AYA males are more likely to die of cancer than AYA females. The leading causes of cancer deaths among AYAs are leukemia and cancers of the central nervous system, contributing to 31% of all AYA cancer-related deaths. Research shows that 84% of AYAs diagnosed with cancer will survive five years past their diagnosis, with the highest survival rates among thyroid, testicular, Hodgkin lymphoma, and melanoma (Prithwish et al., 2011). Survival rates for AYA have not improved when compared to young and older populations (Bleyer, 2011). This lack of improvement is associated with distinct cancer biology, protocol differences in cancer care, longer diagnostic periods, and lower participation in clinical trials (Taylor, Pearce, Gibson, Fern, & Whelan, 2013), as well as inappropriate place of care (Pollock, 2007).

As previously mentioned, the 2009 edition of *Canadian Cancer Statistics* specifically examined AYA cancer. The media release based on the statistics from the Canadian Cancer Society noted several unique challenges for AYA cancer (Canadian Cancer Society's Steering Committee, 2009). These included psychosocial challenges such as coping with changes to bodies and body image (e.g. hair loss, weight gain, issues with sexuality and fertility), feeling isolated and unable to find emotional support, and being overwhelmed by the cancer medical system which is not tailored to the AYA population. Indeed, the majority of AYAs are treated in adult treatment centres, with AYA-specific cancer programs being informed in large part from pediatric cancer (Gupta et al., 2016). The Princess Margaret Cancer Centre is an exception as it has a specific AYA program which is led by a clinical nurse who is specialized in AYA oncology (Gupta et al., 2016). The centre addresses specific AYA concerns in symptom management (e.g. sexual health and fatigue), behaviour modification (e.g. return to work and exercise), and health services (e.g. patient education, advanced cancer, and survivorship). Other issues include delays in diagnosis as a result of AYAs not seeking medical help promptly and healthcare professionals being less familiar with AYA cancer symptoms, different responses to treatment, lower participation of AYAs in clinical trials, falling in-between treatment protocols for treatment of childhood and adult cancers, limited opportunity for prevention, and possibility of future health problems (Canadian Cancer Society's Steering Committee).

In Canada, AYA cancer occurs between the ages of 15 and 29 (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2015), while in the United States AYA cancer occurs between the ages of 15 and 39 (Adolescent and Young Adult

Oncology Progress Review Group, 2006). The AYA designation groups adolescence, the period between childhood and adulthood (Kaplan, 2004) highlighted by the beginning of physiological pubertal changes (Sacks, 2003), with young adulthood. WHO (2015a) however, defines adolescence as occurring between the ages of 10 and 19. Arnett (2000) argues that that the period between the ages of 10 and 18 is defined by commonalities in the adolescent’s residence (i.e. most live with their parents/guardians), pubertal physical changes, secondary school attendance, and their inclusion in a school-based peer culture. Cancer organizations have also begun to be established specifically for young adult cancer, such as Young Adult Cancer Canada (2016) which caters to patients between the ages of 18 to 39, and Stupid Cancer (2016), which does not specify an age range, but generalizes its population as “young adults”. A summary of the varying definitions for AYA can be seen in Table 1.

Table 1

Definitions of AYA

	<u>Age Range</u>	<u>Source</u>
AYA	15-29	Canadian Cancer Society
AYA	15-39	AYA Oncology Progress Review Group, United States
Adolescence	10-19	World Health Organization
Adolescence	10-18	Arnett (2000)
Young Adult	18-39	Young Adult Cancer Canada
Young Adult	Unspecified	Stupid Cancer

Research has tended to group adolescence and young adulthood together as AYA, leading to studies that include a wide range of ages and varying populations, and thus difficulty in understanding statistics for narrower age ranges.

Emerging Adulthood

Emerging adulthood is the age span of 18 to 25 (Arnett, 2000). This developmental theory is based on Erikson's stages of psychosocial development (1950; 1968), Levinson's novice phase of human development (1978), and Keniston's theory of "youth" (1971). Although Erikson did not specify ages in the developmental phases he described, he did write of adolescence and young adulthood, and how industrialized societies have created a prolonged adolescence. Levinson proposed the novice phase as part of human development, which occurred between the ages of 17 to 33 and was characterized by instability and a great deal of possibilities. Keniston created the theory of youth, describing it as the period between adolescence and young adulthood, and characterizing it by a time of "tension between self and society" (1971, p. 7) and "refusal of socialization" (p. 7). This characterization reflected the protestation of the role the United States was playing in the Vietnam war at the time. The socio-emotional characteristics of emerging adulthood distinguish it from AYA. After the age of 18, peer group influences tend to decline and the individual reaches the age of majority. Although the age of majority is reached at either 18 or 19 depending on which province in Canada an individual resides in, he/she is considered an adult at age 18 by federal standards. At the age of 18, an individual can vote, sue or be sued in his/her own name, get married, be charged as an adult, and his/her parents' custody can no longer be enforced (Justice for Children and Youth, 2012). Arnett disagrees that those between the ages of 18 to 25 should be classified as young adults since the term "young adulthood" implies that adulthood has been reached. Although Arnett's definition of the end of adolescence

occurring at age 18 is similar to the definition set by WHO (2015a), Arnett's theory adds to research as it highlights a specific, developmental life phase.

In the past, people in their twenties were relatively predictable: they finished their education, moved out of the parents' household, married, and had their first children typically by the age of 25 (Tanner & Arnett, 2011). Since the 1950s, and even more so since the 1980s and 1990s, there has been a change in the progression to adulthood, with growth in post-secondary education participation (Tanner & Arnett), and an increase in the median age of first marriage to 30 in most industrialized nations (Mathews & Hamilton, 2009). In the late 20th century, it became increasingly difficult to secure a well-paying job with little to no education, which led to post-secondary education becoming a standard for access to a good career path (Furstenburg, 2010). The pattern in the 21st century thus far is for less-educated young adults to live with their partners, despite a desire for marriage, and well-educated young adults to wait to marry until they are older (Cherlin, 2010; Hymowitz, Carrol, Wilcov, & Kaye, 2013). Compared to 1960 when almost half of males and two-thirds of females had reached the milestones of education completion, leaving home, entering the work force, marrying, and having children by the age of 25, only 8% of males and 16% of females had done the same in 2010 (Furstenberg, 2015).

In a survey at the University of Chicago, the majority of students stated that adulthood began at the age of 26 (Harms, 2003). At the age of 18, EAs are more likely to answer the question "Do you think you have reached adulthood" with "in some ways yes, in some ways no" than "yes", with this slowly reversing as they reach the age of 25 (Arnett & Schwab, 2012). Arnett (2007a) therefore stipulates that young adulthood is a

more accurate depiction of the thirties to early forties. EAs experience life changes including leaving home (Goldscheider & Goldscheider, 1994; Mann-Feder, Eades, Sobel, & DeStefano, 2014), personal development in the areas of religion, sexuality, and personal relationships (Lefkowitz, 2005), and increase in self- and other-perceived autonomy (Lamborn & Groh, 2009). Arnett (2004) states emerging adulthood is a time when individuals are feeling in between adolescence and adulthood, engaging in identity exploration, are self-focused, experiencing instability, and are optimistic about the possibilities in their lives. Emerging adulthood, in essence, differs from adolescence and young adulthood by its heterogeneity (Arnett, 2000). EAs can hold different types of residence (i.e. living with their parents/guardians or living alone or with roommates in a dorm, apartment, or house), are unlikely to follow a peer-based group culture, and are not defined by specific physical changes.

Five main features. There are five main features that distinguish emerging adulthood from adolescence and adulthood: (1) identity explorations; (2) instability; (3) self-focus; (4) feeling in-between; and (5) possibilities (Arnett, 2004).

Identity explorations. Adolescence has been typically viewed as the life stage which is important in identity exploration; industrialized societies tend to have a prolonged adolescence (Erikson, 1950). It is logical, therefore, that identity exploration would continue into emerging adulthood. There are three areas of identity exploration which are important to EAs: (1) love; (2) work; and (3) worldviews (Arnett, 2000). By exploring the possibilities that exist within these three areas, EAs are able to understand what they want in life and are able to move toward concrete decisions. Communication in

interpersonal relationships has been found to be important for identity during this developmental stage (Veksler & Meyer, 2014).

Instability. With exploration comes the unknown. At the age of 18, emerging adults are finishing secondary education and are potentially leaving home to either go on to post-secondary education or to find their place in the world (Goldscheider & Goldscheider, 1994). In the United States, the majority of EAs leave their parents' home at the age of 18 or 19, which is much lower than previous decades where children generally did not leave the home until they were ready to marry (Arnett, 2015). Changes in residence are frequent during the early twenties as individuals move out of their parents' home and have the potential to move between university/college residence dorms and/or lodgings with roommates or significant others. EAs also have the tendency to move between living independently and returning to their parents' home. It has been found that the reasons EAs will return home is to transition between post-secondary education and their career, to save money after the novelty of living on their own wears off, to regroup after relationships end, especially in the midst of divorce, and between periods of military service (Arnett).

Self-focus. Being self-focused does not necessarily mean that EAs are selfish. People tend to equate self-focus with self-centredness; each of which are separate entities. Arnett (2007b) believes that being self-focused enables emerging adults to understand what works for them and what they truly want, leading them to a happier and more fulfilled life, as the focus changes toward family and others. Indeed, emerging adults are not as selfish as adolescents and begin to view their parents as actual people with feelings, thoughts, and desires (Arnett, 2004). They begin to view their parents as

individuals with characteristics, both good and bad (Arnett, 2015). Parents also begin to see their EA children as individuals are well, and not merely as their children (Arnett, 2015).

Feeling in-between. Those between the ages of 18 to 25 feel that, although they are adults in some aspects, in others they are not; yet they inherently know that they have surpassed adolescence (Arnett, 2005). This in-between feeling is attributed to the gradual changes which EAs experience, rather than specific milestones reached at specific ages, thus leading to a progressive journey to adulthood, rather than a sudden attainment (Arnett). Previously, marriage used to be the used as a gauge for when adulthood was reached; now EAs feel that accepting responsibility and becoming financially independent are the most important ways in which they feel that they have become adults (Arnett & Schwab, 2012). The goals which the EAs are working to achieve are part of changing relationships with their parents, which creates the feeling of being in-between two stages of life (Arnett, 2015).

Possibilities. Emerging adulthood represents a time for possibilities as it is marked by high optimism and potential, and it lends itself to experiences that are different than those experienced in parents' homes (Arnett, 2005). EAs are able to make their own decisions, choose their own activities and relationships, and shape their own futures. In the *Clark University Poll on Emerging Adults*, EAs described the time in their life as "fun and exciting" characterized by "a great deal of freedom" (Arnett & Schwab, 2012). Approximately 90% of EAs agreed to the statement "I am confident that eventually I will get what I want out of life" as well as the statement "At this time of my life, it still seems like anything is possible" (Arnett & Schwab).

Emerging adulthood, as a defined developmental life stage with specific experiences and challenges associated with it, is important to study in relation to how parents experience their child's cancer. This life stage could have particular impacts on parents psychosocially, especially when cancer is present, as there has already been research which has shown that interactions between parents and children are different during emerging adulthood than other life phases (Arnett & Schwab, 2013). It is not necessarily the type of cancer that is of importance during emerging adulthood, but rather the developmental life stage itself. The limited research and knowledge on emerging adulthood, specifically parents of EAs with cancer, is understandable as this is a relatively newly defined developmental stage.

Given EAs' legal status as adults and their changing perception of parents as individuals who have their own feelings, emotions, and thoughts, there is the potential for EAs with cancer to have a different relationship with their parents than if they were healthy, or if they were young children. Parents of EAs with cancer are likely to struggle with allowing their children to hold on to their independence and make their own decisions regarding cancer treatments and regimens. These factors could contribute to high stress and decreased psychosocial functioning in parents, as well as a change, either positive or negative, in the parent-child relationship.

Issues Specific to Parent-Child Relationships in Emerging Adult Cancer

Examining parents' experiences based on their child's developmental stage versus their chronological age allows this study to be more focused on the psychosocial issues at hand. The main task of emerging adulthood is to become independent, which is the one task that would be most likely impacted by cancer, or other serious illnesses. This is

because cancer provides additional challenges for both the parent and the child, moving the focus away from the developmental task of independence and instead toward the illness itself.

Given the unique challenges that EAs face when diagnosed with cancer, the changing parent-child relationship during the EA life stage, and the five distinct features of emerging adulthood, it is important to understand the issues that could occur in EA cancer for parents. These issues explain why parents of EA children with cancer could experience psychosocial challenges when their child is diagnosed, and throughout the cancer journey.

Disagreement about what constitutes an adult. Parents, much like their EA children, do not view their children as adults (Nelson et al., 2007). Previous studies which looked at the perceptions of EAs about what constituted an adult found that the four top criteria were (1) being independent and self-reliant, both in autonomy and financially; (2) being able to form and maintain mature relationships, specifically with parents; (3) being able to comply with societal norms, such as avoiding criminal activity; and (4) being able to provide and care for a family, such as a partner and/or children (Arnett, 1998; Nelson & Barry, 2005). These criteria remain stable across cultures, including China (Nelson, Badger, & Wu, 2004), Argentina (Facio & Micocci, 2003), Israel (Mayseless & Scharf, 2003), and Aboriginal Canadians (Cheah & Nelson, 2004). Nelson et al. (2007) found similar results in a study of EAs and their parents in the United States. The researchers found that EAs agreed the following statements described the criteria to reach adulthood: (1) “accepting responsibility for the consequences of your actions”; (2) “establishing relationship with parents as an equal adult”; (3) “financially independent from parents”;

and (4) “decided on beliefs/values independently of parents/other influences.” For mothers, the top four criteria for adulthood were: (1) “accepting responsibility for the consequences of your actions”; (2) “avoid drunk driving”; (3) “avoid committing petty crimes like vandalism and shoplifting”; and (4) “become less self-oriented, develop greater consideration for others”. Fathers had a similar result, with criteria two and three being reversed. The results show that both EAs and parents, regardless of gender state that the top criterion necessary for reaching adulthood is accepting responsibilities for the consequences of individual actions. In addition, both EAs and parents alike rated norm compliance as more important for female children than male children, and biological/age transitions more important for male children than female children.

Differing perspectives. Grinyer (2009) studied young adults aged 18 to 25 and their parents. The young adults she worked with are the same age as the development life phase of emerging adulthood, although she did not specifically conduct her studies using that context. Going forward, Grinyer’s young adult participants will be referred to as EAs for the purpose of this research.

Grinyer (2009) found that parental perspectives on the cancer experience are not in alignment with those of EAs. For parents, medical attention was paramount and, as long as the medical care given was believed to be the best available, the location of where the medical care was given was secondary. This contrasted with EAs who were uncomfortable being treated in either pediatric wards or general oncology wards where the majority of patients were much older than them. Changes to appearances that result from cancer were very high on the list of concerns raised by EAs, while parents did not pay much attention to this. Through discussion of the cancer diagnosis, treatment, and

outcomes with their parents, EAs often find that they have different coping strategies than those of their parents (Zebrack, Chesler, & Penn, 2007). As a result of potentially different perspectives, EAs may refrain from vocalizing their thoughts and emotions regarding the cancer experience to their parents. This could lead to increased stress, friction, and misunderstanding in the parent-child relationship.

Parental control and loss of newfound independence. Once a child reaches the age of 18, parents in Canada no longer have legal rights over their child (Justice for Children and Youth, 2012). Parents tend to have difficulty during the EA stage when they must come to terms with the adult status of their children (Aquilino, 2006). Considering the importance of exploration and experimentation within the EA phase, many parents feel that they still need to participate in “parenting” activities in order for their children to adequately navigate this phase and achieve adulthood (Nelson, Padilla-Walker, Christensen, Evans, & Carroll, 2011). Parents who balance yielding autonomy with provision of support and advice create benefits for their EA child and their parent-child relationship (Padilla-Walker et al., 2013). Some parents, however, attempt to control their EA children which results in negative effects for both the EA child and the parent-child relationship (Padilla-Walker et al.). Urry, Nelson, and Padilla-Walker (2011) found that when mothers exerted psychological control over their EA child, it led to the child having a negative perception of the mother-child relationship and the child being less likely to disclose to the mother.

In a study in the United States, Nelson and colleagues (2011) grouped parents of emerging adults into three clusters of parenting: (1) uninvolved, where they were low on both control and responsiveness; (2) controlling-indulgent, where they were high in

control and low in responsiveness; and (3) authoritative, where they were low in control and high in responsiveness. In a study of undergraduate students and their parents, Padilla-Walker and colleagues (2013) aimed to understand perceptions of legitimate authority from both the child and his/her parent. They identified three groups: (1) shared control; (2) personal control; and (3) parental control. Two thirds of parents fell into the shared control group. This group was characterized by their affording their parents a degree of control in their lives, specifically in non-personal domains, which led to a positive parent-child relationship. A quarter of participants were in the personal control group as they did not believe that their parents had a right to any authority in their lives. This group reported the most negative parent-child relationships and the lowest levels of financial support. Only 11% of participants fell into the parental group where EA children had not captured their independence and, as a result, looked to their parents as an authority in all areas of their lives. Although the EA children in this group report the greatest amount of helicopter parenting among the three groups, the parents reported a lower level of legitimate authority than their children did. Issues with parental control can be exacerbated when their child is diagnosed with cancer, leading to difficulties allowing their child to retain his/her independence and freedom (Grinyer, 2006).

Grootenhuis, Last, De Graaf-Nukeker, and Van Der Wel (1996) proposed that parents attempt to exert control in four ways when faced with a diagnosis of cancer in their child aged 8 to 18: (1) predictive; (2) vicarious; (3) illusory; and (4) interpretive. First, predictive control describes how parents attempt to predict the course of the cancer's progress and treatment in order to achieve success over the disease. This control is observed in attempts to know the expected course of the illness and treatment schedule.

Second, vicarious control describes parents attempting to control the decisions the doctor makes regarding treatments. They may also try to prolong treatment even when survival is no longer possible. Third, illusory control is seen through lifestyle changes (e.g. diet and exercise) and seeking alternative health care in hopes of influencing chance-determined outcomes. Finally, interpretive control is when parents attempt to gain as much information as possible in order to improve their own medical knowledge about the situation. Stifled by parents' overprotective behaviour, many EAs were found to engage in behaviours that were deemed "risky" by their parents (Grinyer, 2009). Parents may subsequently engage in overprotection, which is characterized by "overindulgent, over solicitous, overprotective, and overanxious parenting behaviours" (Hullman, Wolfe-Christensen, Meyer, McNal-Knappe, & Mullins, 2010, p. 1374). Parents are more likely to be overprotective when they view their children as vulnerable or having a lower health-related quality of life (Hullman et al.).

Whether or not a child still lives at home or within close proximity to his/her parents may have an effect on the parent-child relationship prior to a diagnosis of cancer. Co-residency rates have been found to vary based on culture and ethnicity. Compared to non-Hispanic whites in the United States, Asians, Blacks, and Hispanics are more likely to live with parents as EAs as a result of lack of socioeconomic resources and cultural attitudes (Britton, 2013). In the 20th century, physical proximity to parents for American EAs in their early twenties has been found to be inversely related to the quality of relationships with them; EAs with frequent contact to parents tended to have poorer parent-child relationships and psychological adjustments (Dubas & Peterson, 1996; O'Connor, Allen, Bell, & Hauser, 1996). In the 21st century, both EAs and parents alike

are reporting their parent-child relationships as significantly more positive than they were during adolescence and 56% of parents are in almost daily contact with their child (REFS). In the United States, an increase has been seen in the number of EA children that have weekly contact with their parents. In 1986 52% of EAs had weekly contact with parents, compared to 62% in 2008 (Fingerman, Cheng, Tighe, Birditt, & Zarit, 2012).

EAs can find independence through moving out of the family home, going to university, or engaging in the workplace. Independence is not entirely complete, however, as many EAs still rely on their parents for financial assistance, whether they live with them or not (Fingerman & Yahirun, 2014). Through the 2008 United States Family Exchange Survey, it was found that 85% of children aged 18 to 28 received financial assistance in the past year, which had increased from 75% in 2001 (Fingerman & Yahirun). Independence is especially complicated for those emerging adults who have left their parents' home, as they are trying to be autonomous, yet still maintain a connection with their parents (Kins, de Mol, & Beyers, 2014). Parents of EAs noted that 56% of them are in contact with their EA child "every day or almost every day" and 73% describe the parent-child relationship as "mostly positive" (Arnett & Schwab, 2013). It should not be surprising then that EAs are likely to seek out their parents for advice and social support during this phase of their life (Cooney & Uhlenberg, 1992). The conflict, however, could occur when parents offer advice or support that is unwelcome and uninvited (Carlson, 2014).

EAs may have difficulty relinquishing their independence when faced with a cancer diagnosis (Grinyer & Thomas, 2001). Many EAs who are diagnosed with cancer must become more dependent on their parents than they were previously, even if just

temporarily (Zebrack et al., 2007). Grinyer (2009) found that many EAs with cancer had to yield their independence and autonomy by returning home. Some require dressing and bathing, which is akin to infantile dependence, and can result in emotional and physical dependency on parents (Grinyer & Thomas). Even for those EA children who did not have to revert to infantile dependency, parents had difficulty allowing them to maintain their independence and, once treatment ended, to regain any independence that was lost (Grinyer, 2009). In many cases where parents experience difficulty with allowing their children to become autonomous, it is not necessarily as a result of their child's behaviour (i.e. seeing their child as too immature); rather, parents feel an overwhelming need to hold on to their parental role (Kloep & Hendry, 2010).

Medical decisions making. In Canada, mental capacity signifies the ability to make medical decisions (Evan & Henderson, 2006). Quebec is an exception, as the legal age for medical decision making in that province is 14 (National Assembly of Quebec, 2013). It is not until reaching the age of majority, however, that individuals tend to feel entitled to exclude their parents from medical information (Grinyer, 2006). In Canada, many EAs are still covered under their parents' health insurance policy, if they have one, until they reach the age of 21 or 25 if a full-time student (Nova Scotia Public Service Commission, 2016; Sun Life Financial, 2016). The United States passed the Affordable Care Act in 2010 which stipulated that children aged 18 to 26 are to remain on their parent's health insurance plan, regardless of their student status (White House, 2013). Although parents make take on a caregiving role when their EA child is diagnosed with cancer, they are not entitled to medical information or decision-making. This understanding that their children can make their own medical decisions can add to

anxiety (Grinyer & Thomas, 2001). Grinyer (2006) found that many emerging adults lacked the appropriate experience in medical decisions or procedures to be fully informed when making treatment decisions. There may be a struggle between the parent and child about who should be making the decisions regarding the cancer treatment and who is more knowledgeable about the situation in general. Parents feel that they should be involved in their EA child's life during emerging adulthood, specifically in activities that typically used to fall under their parental role (Arnett, 2000). Since they are the parent, they have difficulty letting go of the belief that they should be allowed participation in decision-making (Padilla-Walker, Nelson, & Knapp, 2013).

Another issue in regards to medical decision making could stem from the potential risk of infertility for EAs as a result of cancer treatments. As emerging adulthood is the developmental phase between the ages of 18 and 25, it is possible that these emerging adults have not had children of their own, and they may have to consider fertility options should they require cancer treatment that carries the risk of infertility. Infertility for women means being unable to produce eggs, or the inability to conceive or carry a pregnancy to term; for men, infertility means being unable to produce an adequate number of sperm, or producing sperm which are damaged and are not naturally able to fertilize (Fertile Future, n.d.). Cancer treatments that can cause infertility include certain types of chemotherapy, radiation to the whole body or abdomen/pelvic region, and surgical procedures of the reproductive system (Fertile Future). Fertility options should be explored during consultation with the medical team about cancer treatment, and a decision made whether the patient will undergo fertility treatment prior to or after cancer treatment, or if they will reject fertility treatment entirely (Fertile Future). Decision

making about fertility preservation could cause discomfort and friction in the parent-child relationship. This could be as a result of incompatibility between the parents' and child's ideas of what is best, what matters most, and if fertility preservation is important.

Considering these unique challenges, including the number of transitional issues that arise during emerging adulthood, as well as the likelihood that emerging adults have not completely separated from their parents in terms of autonomy and independence, parents of EAs with cancer are an interesting population to study.

Effects of Cancer on Parents' Psychosocial Health

Depending on the type, cancer can be an unpredictable disease which can result in multiple experiences of remission and recurrence. Survival estimates are very general, varying widely by the stage of cancer at diagnosis (Canadian Cancer Society, 2010). Far from being contained to the physical effects, cancer can lead to emotional issues, changes in relationships, roles, and responsibilities. The diagnosis of cancer reaches past the effects on the patient, and can affect the parent of the individual.

The trend of existing literature about cancer's effects on parents is to focus on pediatric (i.e. age 0-15) cancer. Research has indicated that cancer can have effects on physical, mental, and social well-being, as well as coping styles and experiences of death and bereavement. We need to understand how cancer affects the parents of EAs, rather than only those of young children. Research on pediatric cancer can suggest how parents of EA children with cancer may be affected.

Physical health. Being faced with a cancer diagnosis in their child can lead to negative health effects for parents. Overall, parents of children 18 years or younger with

cancer reported a significantly lower quality of life than population norms (Klassen et al., 2008). A study of mothers of EAs with cancer found that the mothers tended to neglect their own health needs (Grinyer, 2006). Fletcher and colleagues (2010) studied mothers of pediatric cancer patients, aged 9 months to 16 years, and found that the mothers experienced health issues which they often ignored or left untreated. These issues were sometimes exacerbated by the mothers engaging in unhealthy behaviours to cope with stressors. When their child has cancer, parents are more likely to follow an unhealthy diet, engage in less physical activity and more sedentary behaviour, and experience sleep disturbances (Klassen et al., 2008; Smith, Baum, & Wing, 2005). As a result, they are likely to experience unhealthy weight gain. Parents of children with cancer gained more weight over a three-month period than parents of healthy children (Smith et al.). When compared to population norms in the United States and the state of Washington, parents of children with cancer were more likely to engage in binge drinking, which was defined as having four or more drinks one or more days per week (Rosenberg et al., 2013).

Mental health. Given the unpredictability of cancer's timeline and outcomes, it is likely that parental mental health would be affected. Thoughts that the cancer treatment may not work or that the child will experience a relapse after remission can lead to feelings of hopelessness and uncertainty in parents (Bayat, Erdem, & Gül Kuzucu, 2008). Despite not being ill themselves, parents of children with cancer can experience psychological symptoms similar to those of patients with other chronic illnesses, which can lead to decreased subjective health perception and life satisfaction (Fotiadou, Barlow, Powell, & Langton, 2008). Parents of both adult and adolescent children with cancer have

reported that, upon diagnosis of their child, they experienced tumultuous emotions (Schweitzer, Griffiths, & Yates, 2012; Val Humbeeck et al., 2015).

Cancer has been shown to be more detrimental to parents' mental health than other chronic illnesses, such as diabetes (Boman, Viksten, Kogner, & Samuelsson, 2004). Parents of children with cancer experience a higher degree of uncertainty than those of children with diabetes, which can be explained by parents of children with diabetes being able to become better acquainted with the disease and feel more comfortable with the diagnosis and prognosis. Cancer evokes the fear of death. Parents of children with cancer face the potential threat of losing their child, whereas parents of children with diabetes do not tend to face this threat. In addition, parents of children with cancer feel a higher degree of loss of control and suffer negative impact on their self-esteem as the care of their child is essentially handed over to the medical treatment team. This is unlike parents of children with diabetes, who normally assume care of their child's treatment (Boman et al.). Coffey (2006) conducted a metasynthesis to understand how parents of children with chronic illnesses were affected, and found that there were mental health effects as a result of the chronic illness. Five of the eleven articles that he reviewed showed that worry and anxiety were evident in parents of children with chronic illness, including those with spina bifida and cystic fibrosis. The worry and anxiety was related to not only the child's current illness, but also changes in health status, and potential issues in the future, such as who would care for the child when the parent was no longer able to. Senger, Ward, Barbosa-Leiker, and Bindler (2015) studied parents of children with mitochondrial disease, which results from problems with cellular metabolism in the mitochondria and can lead to eventual organ dysfunction or failure (Haas et al., 2007), to

understand their experiences of caring for their child. Using the Parent Experience of Child Illness (PECI) a 25-item self-report used to measure parental adjustment when caring for a child with a chronic illness, they found that their child's future and the illness worsening were the reasons parents worried the most often.

Immediately after diagnosis, parents of children aged 0 to 18 with cancer in Australia were shown to have high acute stress levels (McCarthy, Ashley, Lee, & Anderson, 2012). Although psychological distress among parents appears to decline after the initial diagnosis (Dalhquist, Czyzewski, & Jones, 1996; Hoekstra-Weebers, Jaspers, Kamps, & Klip, 2001), distress levels at one-year post-diagnosis are still higher than in parents of healthy children (Hoekstra-Weebers, Jaspers, Kamps, & Flip, 1998; Hoekstra-Weebers et al., 2001). In a study of 122 mothers and 190 fathers from 130 families where the child (aged 1-18) was in remission, it was found that two months after treatment cessation, 72% of mothers and 60% of fathers reported clinically elevated levels of psychological distress (Maurice-Stam, Oort, Last, & Grootenhuis, 2008). Six to eight months' post-diagnosis, 20% of parents met post-traumatic stress disorder criteria and 40% were considered at the threshold of post-traumatic stress disorder (McCarthy et al.). Pelcovitz and colleagues (1996) found that 54% of mothers of pediatric cancer survivors in their study met the criteria for post-traumatic stress disorder, compared to 4% of mothers in the control group. Results from studies of parents of adult children with cancer have found that parental stress and worry about their child's health continue into adulthood after they have survived their cancer (Kinahan et al., 2008). If parents remain involved in their child's healthcare throughout adulthood and attend clinic visits with

them, they will remain psychologically vulnerable far past treatment cessation (Hardy et al., 2008).

The many mental health issues that parents of cancer patients experience could be attributed to heightened rumination (Goldbeck, 2001) and a lack of support offered to parents who are unpaid caregivers, which leads to a disconnect between how carers feel and how they may appear to family, friends, and society (Grinyer, 2006). Grinyer found that mothers experienced emotional and physical difficulties when their EA child was diagnosed with cancer, and this was compounded by the lack of support received. When the women did seek help for mental health issues, they found that healthcare providers were quick to offer antidepressants, which were often rejected by the mothers.

Support and coping styles. Resilience is the “process of adapting well in the face of adversity, trauma, tragedy, threats, or even significant sources of stress – such as family and relationship problems, serious health problems, or workplace and financial stressors” (American Psychological Association, 2015). It essentially involves transactions between the person and their environment (Greene, 2002). It can be influenced by a variety of factors, including gender, age, physical and mental ability (Greene). Research has found that those individuals with strong support networks (Steele & Steele, 1994) and caring relationships (Ainsworth, 1989) are more resilient than those who do not have them. Greene, Galambos, and Lee (2004) analyzed interviews of 18 professionals, including MSWs, clinical psychologists, ministers, a physical therapist, a resident counselor, and an emergency personnel trainer. They found that 33% of these professionals believed that attitude was the utmost important factor for resilience, and

over half said that spirituality and/or religion was important when experiencing a stressful and/or disruptive life event.

Posttraumatic growth is the positive growth arising from a struggle experienced by individuals, which can change their perception of self, how they relate to others, and their philosophy about life (Calhoun & Tedeschi, 2014). Posttraumatic growth can increase resilience and level of functioning. Calhoun and Tedeschi summarize the changed perception of self which results from posttraumatic growth as “I am more vulnerable than I thought, but much stronger than I ever imagined” (p. 5). Parents of adolescent cancer survivors reported posttraumatic growth, specifically in the areas of their philosophy about life, perception of the self, and how they treat others (Barakat, Alderfer, & Kazak, 2006). As an example of how experiencing life-threatening illness or situations can cause positive outcomes, heart attack patients reported healthy lifestyle changes following their attack, whereas breast cancer patients reported improved relationships with others (Petrie, Buick, Weinman, & Booth, 1999).

Parents of EAs with cancer need support, either formal or informal, to help navigate the cancer journey effectively and experience less negative effects. In addition to the stress and worry that comes with a cancer diagnosis in their child, parents, and particularly mothers, often become the main caregivers for the EA with cancer (Grinyer, 2006). In a study of parents of pediatric patients aged 5 to 17, 88% of mothers reported caregiving as a major stressor and 69% reported that daily/role functioning, such as paying bills and being concerned about their job, added to their stress (Rodriguez et al., 2011). There are similarities worldwide with Pakistani Muslim parents of children with thalassemia, an inherited blood disorder, reporting that their anxiety and stress increased

as a result of their caregiving responsibilities, negatively affecting their psychological and emotional health (Anum & Dasti, 2016). They felt that they did not have the time to complete everyday tasks or have time dedicated to themselves, creating feelings of hopelessness. Although support from family and friends is high at the time of a cancer diagnosis, there is a sharp decline after six months, when the parents are faced with the chronic stressor of treatment (Hoekstra-Weebers et al., 2001). Fletcher and colleagues (2010) found that support systems allowed mothers to take part in activities that were unrelated to cancer care and that support was often found from healthcare workers, support groups, and chat groups. Support is less likely to be offered when the child is an adolescent or EA (Grinyer & Thomas, 2001), or if the child has a rare diagnosis, an ambiguous prognosis, or if the child's life expectancy is low (Clarke, 2006). Grinyer (2006) interviewed mothers of EAs with cancer and found that the caregiving burden was heightened by the significance of the person for whom they were caring. All of the mothers who were interviewed acknowledged that healthcare workers involved in the care of their children did not recognize the health needs of the mothers.

Chesney and Chesler (1996) analyzed self-reports of 116 parents of children with cancer to understand the meaning of parental coping. The most common theme was parents' ability to manage their emotions, which included acceptance of the illness and maintaining a positive outlook, despite the illness. The second most common theme was dealing with family issues, which included leading as normal a life as possible and sharing thoughts and feelings openly.

General caregiver burden. To understand potential effects that parents could experience when they undertake a caregiving role, examining general caregiver burden

and its effects is important. Kim and Schulz (2008) found that the caregiver burden was greater in those providing care to adult cancer patients than those caring for older persons in general, and was similar to the experience of caregivers of patients with dementia. Those caring for cancer patients have been found to spend over 40 hours per week providing assistance with such activities as daily living, administering medications, providing transportation, preparing meals, managing finances, advocating for health care, and providing emotional support (Beattie & Lebel, 2011; National Alliance for Caregiving, 2009).

Positive social integration and support have been shown to be protective factors for caregivers of those with degenerative diseases, resulting in better mental and physical health, and less perceived stress (Biegel, Sales, & Schulz, 199; Drentea, Clay, Roth, & Mittelman, 2006). In caregivers of adults with spinal cord injury, it was found that the higher the positive social interaction, the lower the impact of caregiver burden; however, if the social interactions were negative and demanding, there was the chance that the caregiver burden worsened (Rodakowski, Skidmore, Rogers, & Schulz, 2012). Social support is an interpersonal process that includes both emotional and instrumental support and is dependent on context (Finfgeld-Connett, 2005). Examples of emotional support can include comforting gestures, physical presence, attentively listening, and normalizing the situation through the use of humour, pampering, and providing opportunities to socialize and have fun. Examples of instrumental support include providing tangible foods and services. Through a meta-synthesis of qualitative studies, Finfgeld-Connett found that non-professionals are generally the preferred social support providers, and recommended that social support networks “include people who share common

experiences, feel a sense of intimate familiarity, are available, and reciprocate support” (p. 7). Emotional and instrumental support, as well as informational support, are considered resources within the stress-buffering hypothesis, which states that social resources will counter potentially negative effects of stressful events (Cohen & Pressman, 2004).

The stress buffering hypothesis is the leading theoretical perspective on social support and “hypothesizes that support reduces the effects of stressful life events on health (i.e. acts as a stress buffer) through either the supportive actions of others (e.g. advice, reassurance) or the belief that support is available” (Lakey & Cohen, 2000, p. 30). When people provide support in an instrumental manner, the caregiver’s coping ability is thought to improve, while the perception of available support by the caregiver can make situations seem potentially less threatening and/or stressful (Lakey & Cohen). The stress-support matching hypothesis proposes that social support which matches the demands of the given stressor will be effective in reducing the effects of the stressor and promoting coping (Cohen & McKay, 1984; Cutrona & Russell, 1990). Similar to supportive actions, perceived support would be most effective if it matches demands of the stressor (Cohen & Hoberman, 1983; Cohen & McKay, 1984). Parental caregivers of children with autism and ADHD were found to have lower levels of psychological distress, better morning cortisol response and fewer physical health grievances when they reported a greater perceived availability of social resources (Lovell, Moss, & Wetherell, 2012). Similarly, parents of children with Tourette’s Disorder reported less caregiver strain when they perceived greater social support than those parents who perceived less social support (Edge Schoeder & Remer, 2007). Social support has been advocated as being a buffer

between the caregiving burden and adverse health-related outcomes. Lovell and colleagues specifically found that perceived social support lessened the effects on the hypothalamic pituitary-adrenal (HPA) axis. Parents of young children with cancer have lower resiliency than population norms, with fewer resiliency resources and higher psychosocial distress (Rosenberg et al., 2014). However, parents of children with cancer experience less depression and feelings of hopelessness when they perceive higher social support (Bayat et al., 2008).

In summary, the challenge of being a parent of an emerging adult with cancer is to negotiate the burdens, while still supporting the child in the essential developmental role of moving from emerging adulthood to full adulthood, or mourning the loss of a child who will never move to the adult stage. This challenge may be met with coping, resilience and posttraumatic growth or may be, ultimately, too difficult.

Marital and social relationships. Relationships provide the context within which support is provided, and can be affected by the stress and/or strain of caregiving, both positively and negatively. Previous research has shown that marital relationships tend to improve when a child is diagnosed with cancer (Barbarin, Hughes, & Chesler, 1985; Lavee & Mey-Dan, 2003). This could be the result of a life-altering event leading to the couple choosing not to take each other for granted, leaning on one another for support, and ultimately becoming a stronger unit. Carrión (as cited in Machado da Silva, Jacob, & Casthanheira Nascimento, 2010), has found a different result, however, showing that high stress in parents of pediatric cancer patients led to a weakened connection between partners. In a study of 18 married biological parents of children with cancer in Brazil, it was found that although parents experienced strain and difficulties in their marriages at

the onset of the cancer experience, these relationships were generally repaired as time went on (Machado Silva-Rodrigues, Pan, Mota Pacciulio Sposito, de Andrade Alvarenga, & Castanheira Nascimento, 2016). As a result of the chaos that cancer brought into their lives, couples generally agree that in the first six months after the diagnosis, and specifically in the first few weeks, they faced the most difficulty in their relationship. As they journeyed through the cancer experience together with their child, they were a united front in overcoming the illness, yet they remained distant in their relationship with each other, as they were focused on their child. Focusing on the positives that came out of the experience, such as encouragement and strength from each other, helped them to believe in a future where their marriage would return to either its original state, or a better one. Given the conflicting literature, the effect of the cancer experience on marital relationships may depend on how strong the couple's relationship was prior to the cancer diagnosis, as well as the type of cancer the child is diagnosed with, including required treatments and potential for remission. In addition, culture could play a role in the different ways that marital relationships are affected as a result of a child's cancer diagnosis. Studies on married couples in the United States (Barbarin et al.) and Israel (Lavee & Mey-Dan) found that marriages improved as a result of the experience of having a child diagnosed with cancer, whereas studies with Brazilian couples found that marriages tended to deteriorate (Machado da Silva et al.), although one study found that, for many, the marriages were rebuilt after the immediate danger had passed (Machado Silva-Rodrigues et al.). Despite the differing results about how the emotional aspects of the marital relationships are affected, it has been shown that intimate and sexual relationships deteriorate for parents (Lavee & Mey-Dan; Machado da Silva et al.).

Socially, parents may limit relationships outside the familial or marital core, as they begin to feel lonely and isolated as a result of the caregiving burden and treatment requirements of their child (Bayat et al., 2008). Relatives who cared for EAs with mental illness found that their caregiving role limited their social relationships because it impacted their ability to make plans; others said they consciously avoided social interactions to focus on the EA's illness (Lindgren, Söderberg, & Skär, 2016).

Death and bereavement. The death of a child has been found to be more stressful for parents than the death of a spouse (Dyrgroven, 1990; Osterweis, Solomon, & Green, 1984) and parents can remain in the acute stage of intense grief for at least four years (Hazzard, Weston, & Gutierrez, 1992). Experiencing the death of a child is akin to experiencing the opposite of the natural order of life; parents are supposed to die before their children (Alam, Barrera, D'Agostino, Nicholas, & Schneiderman, 2012). The death of a child indicates not only a loss of a person but also the loss of future prospects (Kars, Grypdonck, & van Delden, 2011). Parents who had only one child often view themselves as no longer being parents once their child dies (Kars et al.). Once their child dies, parents experience changes in their relationships, as well as personal changes, such as emotions, perspectives, and spiritual beliefs (Gilmer et al., 2012). Over time, mothers and fathers are found to handle their grief differently. Mothers express more intense grief immediately following the death, and become more child-focused whereas fathers become more task- and work-focused (Alam et al.).

In summary, the existing literature shows that parents of children who are less than 18 years of age are affected physically, mentally, and socially as a result of experiencing cancer in their child. Some research, mainly by Grinyer, who looked at the

chronological age of 18 to 25, without taking into account developmental differences, has found that EA cancer affects parents in ways similar physically and mentally to parents of young children with cancer. What the existing literature has in common is that it focuses on a specific time period of the life span based on an age range, rather than a developmental phase. Pediatric cancer focuses on children aged 1 to 14 years (WHO, n.d.) and AYA cancer focuses on children aged 15 to 39 years (National Cancer Institute, n.d.) These are broad ranges that do not take into account specific developmental factors. The developmental phase of the child may be more important than their chronological age when studying the effects of the child's cancer on his or her parents. Emerging adulthood, between the ages of 18 to 25, is derived from developmental theory (Arnett, 2000), and therefore requires closer examination for its effects on parents.

Purpose of Research

The purpose of this study is to begin to understand how parents in Canada are affected psychosocially when their EA child is diagnosed with cancer. For this study, psychosocial describes the psychological factors and social environments which the parents face during a traumatic experience. The effect of these factors on the physical and mental well-being of these parents, and ultimately their ability to function, is what is of interest. A secondary purpose is to inform future support and programs for parents of EA children with cancer, as well as with other chronic illnesses. In addition, it is the intention to create interest in further research designed for the EA population and their families.

The World Health Organization (2015c) defines health promotion as “the process of enabling people to increase control over, and to improve, their health. It moves beyond a focus on individual behaviour towards a wide range of social and environmental

interventions.” To develop health promotion programs, policies, and initiatives, as well as to inform future research, the social determinants of health for any social or human problem need to be examined. The social determinants of health are “the conditions in which people are born, grow, live, work, and age” (WHO, 2015b). The cancer experience may affect parents’ lives, including their social system, work life, and interactions with the healthcare system.

The World Health Organization (2015d) organizes the determinants of health into three broad categories: (1) the social and economic environment, (2) the physical environment, and (3) the person’s individual characteristics and behaviours. Included in these categories are income and social status, education, physical environment, social support networks, genetics, health services, and gender. It is important to recognize how the social determinants of health are impacted for parents of EA children with cancer in order to best understand how this population can be managed to decrease negative health effects and to provide proper programs and support.

The determinants of health which were of particular interest in this study were primarily social support networks and access to health care, as well as physical environment (i.e. working conditions), gender, and self-care. In the discussion, each of these will be examined in relation to the results that were found for each case.

Research Questions

There are two central questions to this study, with several sub-questions within each.

How does having an emerging adult child with cancer affect the parent psychosocially? The overarching purpose of this study is to understand the psychosocial effects on the parent when he/she experiences a diagnosis of cancer in his/her EA child. EAs face a variety of unique challenges and experiences given their developmental phase (Arnett, 2000). Once they reach 18, EAs share the same legal rights as adults, with the exception of alcohol and tobacco consumption in some provinces. They are also leaving home and experiencing the world on their own terms. In emerging adulthood, autonomy and relatedness have been found to be complementary to the parent-child relationship (Arnett).

Mothers of children aged 14 months to 21 years who take over the caregiving role have been found to neglect the relationships outside the mother-child pairing (Clarke, 2006). Grinyer (2006), who studied mothers of EAs with cancer, found that, as a result of being unpaid caregivers, the mothers experienced feelings of isolation as their social world diminished. There may also be a struggle with guilt over maintaining normal relationships when the child is suffering. Studies have shown that parents of young children with cancer have experienced negative mental effects as a result, such as psychological distress, anxiety, stress, and worry, which results in negative physical health (Bayat et al., 2008; Fotiadou et al., 2008; Klassen et al., 2008; Rosenberg et al., 2013; Smith et al., 2005).

Given this information, four specific sub-questions fall under this research question: (1) What are the issues specific to the child being an emerging adult that contribute to any psychosocial effects; (2) From the parental perspective specifically, how is the parent-child relationship affected by the experience – given the status of their

relationship with their child prior to diagnosis, do these parents feel that their relationship was helped or hindered by the cancer experience; (3) How are the parents' other relationships (e.g. social, family, marital) affected by the experience – are parents able to maintain their relationships in a normative and functional way, or are they hindered or helped by the experience of cancer and, if so, how; and (4) How does the experience affect the parents' mental health (e.g. stress, anxiety, depression).

What support is important to parents of emerging adults with cancer? The second purpose of this study is to understand how parents in these circumstances may be supported. Support is less likely to be offered when the child is not a pediatric patient (Grinyer & Thomas, 2001). Parents of emerging adults are unique in that their child is not a pediatric patient who requires parental decision-making and caregiving, nor has their child reached a stage in which he/she is completely confident in his/her status as an adult. Support can come from a variety of sources, such as family and friends, nurses and hospital workers, support organizations, and counselling groups. Parents may also not be well positioned for support as medical personnel may not know that they are involved in the cancer experience. Friends of the parent may be less likely to know that the child is ill if that child does not live at home. As explained previously, social support specifically is hypothesized to have a buffering effect on caregiving burden, lessening its effects.

It is important to understand what supports been found helpful in order to guide the implementation of proper supports for parents of EA children with cancer. There are two specific sub-questions which fall under this research question: (1) What supports have parents experienced that were beneficial to them; and (2) What supports do parents feel are lacking and could benefit them or other parents in similar situations?

About the Researcher

I am a Caucasian, female researcher in my mid-twenties who has an undergraduate degree in psychology and an interest in health promotion, chronic disease, cancer, and mental health. My undergraduate research allowed me to become familiar with the EA population in an unrelated topic of study. Through my previous research I came to understand the lack of literature in the EA field. As a result of my experience volunteering and working with Breast Cancer Action Nova Scotia (BCANS), as well as my personal experiences regarding the effects of diseases on family members, I decided to study parental responses to EA cancer.

BCANS (2016) is “an organization of survivors and supporters that focuses on the concerns and needs of those affected by breast cancer through support, education, networking, and advocacy.” I volunteered with BCANS for a year as a Live Pink Teen Breast Health blogger prior to becoming employed as the Director of Programming and Communications. Through my work with BCANS, I met many women and men who have been diagnosed with breast cancer, as well as their family members and friends who have been affected by the diagnosis. As a result of speaking with these individuals and helping them find the resources they needed, I came to appreciate the burden that cancer has on the lives of not only the patient, but on the lives of all of those who surround them.

My personal experience with cancer is limited. I have been fortunate to not have any family members diagnosed with cancer. When I was younger, I had a family friend who was diagnosed with bone cancer, and I saw the effect it had on his wife and two young daughters, as he went through treatment, amputation, and eventually, died. I have had friends who have struggled with illnesses and diseases, and have seen their parents

worry over their child's care and treatment. I, myself, have chronic illness which is generally non-life-threatening, but have nevertheless observed my mother worry and attempt to exert some parental control, specifically regarding medication, even into my EA stage.

My life observations and work with BCANS generated a great interest in the effects of cancer on the patient's support system. I did believe that parents of EA children with cancer would experience their journey differently than parents of young children with cancer, as I understand as an EA that it is a period of transition that can cause conflict and imbalance between parent and child. I thought that, should cancer be involved, this conflict would potentially increase. When thinking of the differences between parents of EA children with cancer versus EA children with other chronic illness, such as asthma or diabetes, I thought that cancer would have more of an impact. My preconception was as a result of noticing the impact that breast cancer had on the patients and their families through my work at BCANS. Cancer is not an expected illness, and its treatment tends to being quickly and be demanding. When comparing cancer to other chronic illnesses which are long-lasting, may or may not have intense treatment regimens or be life-threatening, it seemed to me as though cancer would have more of an impact.

As a result of me not having personally experienced a loved one being diagnosed with cancer, I was unsure of all the facets and difficulties that may arise. I came into this study as a researcher, and not as an individual with personal cancer experience. This resulted in a struggle between balancing what the research showed, and what my participants experienced. This study has increased my empathy and appreciation of

individualized experiences, and the effect that cancer can have, not only on the cancer patient, but also on those that are close to him or her. In addition, my previous research experience has been quantitative in nature and so it was a struggle to ensure I created rich descriptions of my participants' experiences in order to adhere to the quality and rigour standards of case study methodology, thereby demonstrating credibility.

Chapter 2: Methodology and Methods

To understand how parents of EA children with cancer are psychosocially challenged, a qualitative exploratory approach was taken using an online asynchronous discussion focus group at the commencement of the study. As a result of low enrolment, the methodology was changed to an exploratory collective case study approach (Baxter & Jack, 2008). See Appendix J for original design description. Boundaries were given to select participants. Qualitative semi-structured interviews were conducted either in-person, on the telephone, or over email. Documents were collected from each participant (e.g. photographs, journal/diary entries, blog posts) to add context to each participant's journey (i.e. case). Qualitative methodology was chosen as it provides the opportunity for researchers to explore the meanings that the participants give to the proposed human or social problem (Creswell, 2014). Qualitative methods rely on text and image data, and are well-suited for exploratory topics (Creswell). Being able to understand the range of experiences of participants by allowing them to guide the research allows for better support initiatives to meet the needs of this population (Murray, 1998).

Research Design

Qualitative research is used to create a summary of events which are experienced by individuals or a group of individuals (Lambert & Lambert, 2012). A case study approach, which was used in this study, is the least theoretical of available qualitative designs, as the attempt is to study the phenomenon in a more natural setting than a structured theoretical design would allow

Qualitative research “is interested in the perspectives of participants, in everyday practices and everyday knowledge referring to the issue under study” (Flick, 2007, p. 2),

and provides in-depth, contextually rich data (Creswell, 2014). Qualitative research is well-suited for exploratory research, where the research questions allow for multiple findings to appear, concluding with analysis that leads to a general understanding of the topic (Hesse-Biber & Leavy, 2011).

Methodology. An interpretive, or social constructivist, approach was taken in this study, consistent with the recommendations of leading case study theorists (Stake, 1995; Yin, 2013). Constructivism is the epistemological approach that we can know our world only through transactions between the researcher and the researched, in which the researcher attempts to understand the meaning of experiences to the individual, and the understanding that all experience is socially constructed. It entails that I, as the researcher, have a personal relationship with each case.

Qualitative case studies use a variety of data sources to explore a phenomenon, allowing the issue to be explored using a variety of lenses so multiple facets can be revealed and understood (Baxter & Jack, 2008). Case study design is defined by individual case interest rather than method of inquiry (Hyett, Kenny, & Dickson-Swift, 2014). Within this study, the experiences of three participants were explored through detailed, in-depth data collection using a variety of data sources in order to report a case description and case themes.

Collective case studies allow the researcher to examine the similarities and differences within and between cases (Stake, 1995). Stake (2005) points out that a ‘case’ may be an individual, a collection of individuals in a similar context, or an event. Similarly, Baxter and Jack note, for example, “A single holistic case might be the decision making of one woman or a single group of 30-year-old women facing breast

reconstruction post-mastectomy” (p. 549). Stake (2005) notes various foci of interest for case studies. For this case study, the intention was to study several parents of EA children with cancer for the purpose of understanding the experience of parenting under these circumstances (i.e. the cases of interest for this study were parents of a child with cancer when the child is in a unique, transitional, developmental stage). Stake (2005) refers to such studies as “instrumental” (p. 445). The case itself is of secondary importance, as it facilitates understanding of the subject at hand (Stake, 1995). Stake (1995) states that instrumental study can extend to more than one case as a “multiple” or “collective case study” (p. 445). This type of study enabled me to explore the experience of individual parents, the differences between the individual parents, and the global experience across all parents. It should be noted that one disadvantage of case studies is the possibility of collecting so much data that it is impossible to make sense of it (Baxter & Jack).

The cases were developed in tandem between myself and the participants, with discussion back and forth and engagements resulting in additional documentation for each case. As the participants provided me with documentation or answered my questions during the interview process, I asked them for clarification or to expand. I gave them examples of the documents that they could provide to add richness to their particular experience, although I made it clear to them that they could choose anything they felt comfortable with, whether or not I had listed it. When one participant provided me with pictures of her child, I asked if she would mind sharing a picture of her and her child together, if she felt comfortable. The participant had not thought to share such a picture,

but was willing when I specifically requested it. Each case has been presented to engage the audience and invite them to join in the interaction and discovery (Stake, 1995).

This study took an exploratory collective case study approach. As this is an understudied population, an exploratory approach was taken to develop propositions and reasoning for further research (Yin). This study was defined by its exploratory nature as the main driver was to examine a new phenomenon that has not been studied; I wanted to understand what was occurring for parents who had their EA child diagnosed with cancer. A case study approach allows for more in-depth understanding of each individual participant's experience (Yin). One of my goals as a researcher was to highlight the needs of these parents, so that further, specific, research could be conducted that would lead to health promotion initiatives.

Although an atheoretical approach was taken for data analysis, social support theories from the stress and coping perspective, specifically the stress-support matching hypothesis (Cohen & McKay, 1984) and appraisal theory (Lazarus, 1966), and the theory of emerging adulthood (Arnett, 2000) was used to examine the cases. Once the atheoretical analysis was completed, I used these theories to help me “shed light” on some “theoretical concepts” (Yin, 2014, p. 40). It was important that I did not impose any of my understandings on the data; rather, I sought to be open to what the data had to offer, while acknowledging that I, as a researcher, am interpreting the data and that this process cannot be entirely neutral.

Sampling Strategy

This study utilized purposeful and snowball sampling methods. By purposefully selecting participants, I invited participation by those who fit within the boundaries and

who would help me gain valuable information through in-depth interviews and data collection based on the research questions; I did not engage in random sampling (Creswell, 2014), as I was looking for specific participants which would be able to represent the population adequately. Snowball sampling is when the research participants are asked to refer any individuals that they believe fit the study's boundaries and would be interested in taking part in the study (Atkinson & Flint, 2004).

Boundaries. As Baxter and Jack (2008) and others point out, a key aspect of case studies is their boundedness, including matters such as geographical origin, the nature of the case, and a time period, among others. Both Yin (2013) and Stake (2005) alike have recommended that case studies have boundaries as a way to prevent them from getting too large. Boundaries also enable the researcher to define the case, including what attributes should and should not be included (Stake, 2005). Boundaries are similar to inclusion and exclusion criteria in that they describe the sample that is to be included, yet they also indicate the breadth and depth of the study. For example, this study's breadth is expands Canada-wide, although it specifically targets parents of EA children, rather than parents of any child with cancer. There were four specific boundaries for this study. First, the participant must be a parent of an EA child (i.e. the child had to be between the ages of 18 to 25), who had been or was diagnosed with cancer. Second, the diagnosis which occurred between the ages of 18 to 25 must be the child's first cancer diagnosis. Third, the participant must be a current resident of Canada. Lastly, the participant must be able to understand and communicate competently in English as the study was conducted in English, which was a practical boundary.

Parents. For the study, parents included biological (i.e. those who were genetically related to the child) and adoptive (i.e. those who had legal guardianship of the child through the adoptive process) parents, as well as step-parents (i.e. the spouse of the biological or adoptive parent). Parents from both opposite-sex and same-sex partnerships/families were eligible. All parents from a particular family were eligible to take part in the study. Each participant was asked to mention whether or not another parent of their child was taking part in the study, to the best of his/her knowledge. In this study, the three participants were from three separate families.

First diagnosis and age at diagnosis. The child must have been diagnosed between the ages of 18 to 25, as they must be an EA as defined by Arnett's (2000) theory of development. It must have been the first cancer diagnosis that the child had experienced. Reoccurring cancers did not fit the boundary; this was done as I was looking at cancer occurring specifically in the emerging adulthood life phase, rather than a cancer that had previously been experienced when the child was younger. Parents of children who previously had cancer and had been diagnosed with a new type of cancer between the ages of 18 to 25 were not eligible to participate. These boundaries were selected as the study's purpose was to understand how parents were affected from the experience of their EA child having cancer. By mandating that the first diagnosis of cancer must occur during the ages of 18 to 25, I ensured that the cancer diagnosis was specific to the developmental phase of emerging adulthood.

Resident of Canada. Participants and their children were required to be residents of Canada. Although participants and/or their children were not required to have been born in Canada, they were required to have legal Canadian citizenship. This boundary

was selected because, not only did it restrict the study from becoming too large, it also ensured a measure of homogeneity within the study population, given the differences between health care systems across different countries.

English comprehension. Participants must have been able to understand and communicate competently in English as the study materials, including the interview questions, were in English, and were not validated with other languages (e.g. French).

Sample size. The goal of this study was to have between two to four participants. There were three participants in total. It was the intent that these participants reflect different experiences within the population of parents of EA children with cancer. There was a preference to have cases include a parent of a daughter, a parent of a son, a father, and a parent of a deceased child. It was predicted that one or more mothers would volunteer to participate. Three mothers took part in the study. Two mothers have children who survived their cancer experience; one mother had a son and one mother had a daughter. The third mother had a daughter who died as a result of the cancer. It was thought that a small sample of cases would be adequate for this study, given the small size of the population and the exploratory nature of the study. Morse (2000) suggests that fewer participants are needed in case study research as increasingly rich data is collected from each participant.

Recruitment

Participant recruitment was conducted using various methods. See Appendix J for details about changes in recruitment during the study.

Reddit. Reddit is a social news and entertainment website that allows the general public to both view and post information under specific topic threads. Advertisements (Appendix A) were posted under the threads “Health Project” and “Cancer”. Reddit was used until the change in methodology from an online focus group study to a case study approach; after which it was discontinued as a recruitment method.

Facebook page. A Facebook page was designed and launched for the study when it first began. The page included a picture of the study’s poster, a description of the study including inclusion criteria, contact information for the researcher, and the option for potential participants to leave messages on the Facebook wall or to send private messages. Although the Facebook page was primarily a recruitment tool, it also held the potential to be used as a space for technical troubleshooting from potential participants and/or interested organizations.

Kijiji advertisements. Kijiji is an online classified advertisement website that is open to the general public to both view and post advertisements. Advertisements (Appendix A) were placed under the “volunteer” section on Kijiji sites for multiple locations throughout Canada. Locations that were used included: (1) Nova Scotia: Annapolis Valley, City of Halifax, Cape Breton, Bridgewater, New Glasgow, Truro, and Yarmouth; (2) New Brunswick: Bathurst., Edmundston, Fredericton, Miramichi, Moncton, and Saint John; (3) Alberta: Banff/Canmore, Calgary, Edmonton, Fort McMurray, Grande Prairie, Medicine Hat, and Red Deer; (4) British Columbia: Comox/Courtenay/Cumberland, Abbotsford, Vancouver, Kamloops, Kelowna, Vernon, and Victoria; (5) Manitoba: Brandon, Thompson, and Winnipeg; (6) Newfoundland and Labrador: Labrador City and St. John’s; (7) Ontario: Barrie, Belleville, Brockville,

Cornwall, Guelph, Hamilton, Kingston, Kitchener/Waterloo, London, North Bay, Ottawa, Owen Sound, Peterborough, Pembroke, Sarnie, Sault Ste. Marie, St. Catharines, Sudbury, Thunder Bay, City of Toronto, and Windsor Region; (8) Prince Edward Island: Charlottetown; (9) Quebec: Montreal; (10) Saskatchewan: Regina, Moose Jaw, and Saskatoon; and (11) Territories: Northwest Territories, Nunavut, and Yukon. Locations were chosen as major cities and other areas which created a geographic spread.

Website advertisements and posters. Cancer-related organizations were approached throughout Canada via email to request either a website advertisement or for them to display the study poster (Appendix B, Appendix C). Specifically, the following organizations were contacted for recruitment: Brain Tumour Foundation of Canada, Breast Cancer Action Montreal, Breast Cancer Nova Scotia, Breast Cancer Society of Canada, Canadian Breast Cancer Network, Canadian Cancer Research Alliance, Canadian Cancer Society, Canadian Cancer Survivor Network, Canadian Partnership Against Cancer, Canadian Skin Cancer Foundation, Canadian Virtual Hospice, CancerCare Manitoba, CancerFightClub, Kidney Cancer Canada, Leukemia and Lymphoma Society of Canada, Lung Cancer Canada, Melanoma Network of Canada, Ovarian Cancer Canada, Pancreatic Cancer Canada, Rethink Breast Cancer, Sarcoma Cancer Foundation of Canada, Team Shan, Testicular Cancer, Thyroid Cancer Canada, Willow Breast and Hereditary Cancer Support, and Young Adult Cancer Canada. In addition, community centres and cancer centres throughout Canada were contacted requesting help in recruitment. A blog written by me was posted on the CancerFightClub blog website (Appendix D).

Snowball sampling. As previously mentioned, a snowball sampling technique was utilized as a recruitment method. Participants were encouraged to communicate about the study to others who they believed would be interested and eligible to take part. Participants were able to advertise the study to acquaintances, friends, family, and partners. Although the three participants who took part were given the opportunity to let others know about the study, it is unclear whether they did so. One mother said that she knew another mother who had experienced a similar situation, but felt uncomfortable approaching her.

Data

Due to low enrolment and recruitment issues, the methodology changed to a case study approach, and the method of data collection was altered. All three participants took part in an interview, and they were all requested to submit additional documentation to add more depth to their individual experience. Two of the participants had previously been enrolled in the online focus group and they had provided a portion of their interview through the online discussion board. The interview portion from the online discussion group for both of these participants also included dialogue between the two, where they responded to each other's postings. For one participant, this interview was continued and supplemented via email, as this was the method that best suited her availability. For the second participant, the remainder of her interview was conducted in person, as she was in my area for an unrelated matter. The third participant joined the study once the data collection methods had changed. Her interview was conducted over the phone as she lived in another province. The first participant submitted photographs, a medical journal (i.e. a record of the medications, appointments, and information for her son's cancer

journey). The second participant submitted photographs, a medical journal (i.e. a record of the medicals, appointments, and information for her daughter's cancer journey), and a speech that she gave at a local cancer event. The third participant submitted a blog that her and her daughter co-wrote that included photographs.

As mentioned previously, three different techniques were used for the interview portion of the data collection. Interviews were conducted through telephone, email, and in-person. Interview techniques were chosen based on participant preference, and each have advantages and disadvantages. Telephone interviews are characterized by their synchronized time and unsynchronized place, and can be used to access hard-to-reach populations (Opdenakker, 2006). The use of telephone interviews can increase the sharing of sensitive information, benefit from spontaneous reaction from participants, and can be audio recorded. Social cues, however, cannot be read and analyzed. Email interviews are characterized by unsynchronized time and place and allow access to hard-to-reach populations and an increase in the sharing of sensitive information. They also do not need to be transcribed. Disadvantages include not being able to read social cues and a delay between the questions and answers. In-person interviews are characterized by synchronized time and place, and this is the only interview method which enables social cues to be read and analyzed. It also removes the issue of time delay, can be audio recorded, and allows for the creation of a good interview environment.

Tools. For two of the three cases, data were partially collected using the Blackboard Learn online discussion-based focus group as the participants had enrolled prior to the methods being changed. These two participants were requested to provide additional information (i.e. answering additional questions or questions they had

previously not answered) through an interview, as well as to send documentation of their experience. For the remaining participant, information was gathered through a phone interview and the collection of documentation of their cancer journey (i.e. a blog that was primarily written by her, with entries from her daughter). Table 2 shows the data that was collected from each participant.

Table 2

Data Collected from Participants

<u>Case (pseudonym)</u>	<u>Interview Method</u>	<u>Additional Data Sources</u>
Sandra	Online Discussion-Based Focus Group and Email *original participant prior to change in methodology*	Medical journal Photographs
Laura	Online Discussion-Based Focus Group and In-Person *original participant prior to change in methodology*	Medical journal Photographs Speech given at cancer event
Melanie	Telephone	Blog (including photographs)

Interview. Participants were given the option to have their interview be conducted via email, phone, Skype, or in-person. Interviews included demographic questions and pre-formed unstructured research questions. An interview guide (Appendix E) was used, although deviation was allowed to ensure context was established for each individual.

Participant demographic information. Participants' age, sex, ethnicity, marital status and relationship to child was integral to understanding the basic information about each case. Age and sex are standard demographic questions. Ethnic information was requested as different ethnicities may experience the cancer journey differently, and parent-child relationships during emerging adulthood have already been found to vary by race, ethnicity, and place of birth (Fingerman & Yahirun, 2014). Marital status was

requested as questions about marital and/or intimate relationships were asked during the interview. The relationship to the child was important to understand what parental role the participant played.

Child's demographic information. The child's sex was requested as daughters and sons could have encountered different issues during the cancer journey, creating different experiences for the parents involved. In particular, issues relating to fertility and body image have been found to be more distressing to adolescent females than males (Roberts, Turney, & Knowles, 1998). Information about the child's living situation when diagnosed and after diagnosis was requested to gain an understanding into what level of independence existed for the child, and whether that independence was maintained after diagnosis. In addition, EAs who leave home tend to get along better with their parents afterward, potentially as a result of seeing their parents only when they choose (Arnett, 2004). Considering that research has found that one in three EAs had returned to the parental home, at least temporarily, during the first decade of the 21st century, mostly as a result of the economy (Seltzer, Strohm, & Bianchi, 2011), it is plausible that EAs have continued this trend, for either financial or personal reasons, or during breaks from post-secondary education. With a cancer diagnosis, the likelihood of the EA returning to the parental home could be heightened, given the potential severity of the situation. Grinyer and Thomas (2001) found that, following a cancer diagnosis, many EA children moved back in with their parents, which subsequently forced the family into a living situation they thought they had moved on from. I asked what the child's age was at diagnosis to ensure that the child had been an EA at the time of diagnosis. The time elapsed since diagnosis gave insight into differences between cases. For example, a parent of a newly

diagnosed child versus a parent of a child that was diagnosed 10 years ago. The type and stage of cancer that the child was diagnosed with informed the case, and allowed for an understanding of the expected outcome of the child's cancer, including treatment and mortality. The time elapsed since treatment ended also gave insight into whether the parent was still actively experiencing this journey, or whether she had moved on from the active experience and had moved past it, or still struggled with worry regarding her child's potential mortality.

The bulk of the interview consisted of semi-structured questions. Participants were able to add information as they saw fit, and I was able to ask further questions that expanded on the information they had already shared, depending on the individual. Interview questions were broken down into three sections: (1) personal challenges; (2) relationships; and (3) support.

How might your experience of your son or daughter's cancer have been different if he or she had been a young child, a teenager, or an adult (aged 30 or older)? Research to date has been primarily focused on parents of pediatric cancer patients (e.g. Bayat et al., 2008; Fletcher, 2010; Gilmer et al., 2012; Klassen et al., 2008). Given the developmental theory of emerging adulthood (Arnett, 2000), I believe it was important to see if parents viewed the age at which their child was diagnosed as a specific developmental phase of their child's life. It also gave me insight into the difficulties the parents may have encountered, or felt that they encountered, as a result of their child being an EA at the time of diagnosis. In addition, the question could give insight into whether parents believed that the age of their child made it easier or more difficult for the parent. If participants had difficulty knowing how to answer this question, a prompt was

offered: “Have you considered issues such as independence versus dependence of your child, medical decision making, different perspectives you and your child hold regarding his or her cancer care and his or her abilities as an adult, and parental control?”

Do you believe that the experience of your son or daughter’s cancer has affected you personally and, if so, in what ways? Pediatric oncology studies which focus on parents have found that parents are affected emotionally and physically. Examples include a reported lower quality of life (Klassen et al., 2008), unchecked health issues, sleep deprivation, and engaging in unhealthy behaviours (Fletcher et al., 2010; Klassen et al., 2008; Smith et al., 2005), decreased functioning, psychological distress, and depression (Boman et al., 2004; Dahlquist et al., 1996). If the participant had difficulty answering the question, a prompt was used: “Have you considered both the positive and negative effects that this experience may have caused?” I wanted to know not only the negative effects of the diagnosis on the parent, but also if they had experienced any positive effects, such as personal growth, a greater degree of understanding and empathy toward others, or adopting a healthier lifestyle as an individual, as these are common occurrences in trauma situations.

Has your relationship with your son or daughter been affected by this experience and, if so, how? Depending on their previous relationship with their child, parents could experience a shift in the quality of their relationship with their son or daughter following the cancer diagnosis. As noted previously, conflict could already exist as EA children and their parents tend to disagree on what constitutes adulthood (Nelson et al., 2007), and can be exacerbated during the cancer journey as parent and child disagree on what aspects (e.g. treatment, prognosis, effects on physical appearance) hold more importance

(Grinyer, 2009). On the other hand, the cancer journey could strengthen the parent-child bond, as has previously been shown to occur in a study of parents of children with cancer in Sweden (Lindahl Norberg & Steneby, 2009). Posttraumatic growth can occur for parents with children who have survived cancer, resulting in them treating others in a better manner, including their children (Barakat et al., 2006). There may also be a positive relationship with little to no conflict previous to the cancer diagnosis, and no change to this relationship is experienced. When surveyed, the majority of parents of EA children stated that they felt that their relationship with their child was positive, and had grown increasingly so since their child was in his or her mid-teens (Arnett & Schwab, 2013). If parents had difficulty answering the question, a prompt was used: “Your relationship may have become better, worse, or may have remained the same. Have you considered the ways in which your relationship with your son or daughter may have changed (for example, levels of communication, enjoyment, pride)?”

Has your social and/or work life been affected by this experience and, if so, how?

Parents of pediatric cancer patients have been found to limit relationships outside the family or marriage as a result of the caregiving burden and treatment requirements of their child (Bayat et al., 2008). The caregiving burden could also lead to decreased ability to work or feeling as though it is necessary to leave their employment. In a study of the effects of a child’s cancer diagnosis on the parent’s well-being six months’ post-diagnosis, Sloper (1996) found that, for those parents who were employed when their child was diagnosed, employment was negatively affected for 50% of mothers and 37% of fathers. The finding that more mothers’ employment was negatively affected than fathers is not surprising; mothers generally assume caregiving when their child is

diagnosed with cancer (Clarke, 2006). Although EA children may be more independent than younger children, they may still require parents to provide caregiving to them during cancer, which could lead to changes in parents' social relationships and employment. Caregiving parents of EA children with mental illness have reported that social relationships are hard to maintain as plans were difficult to make, and there was a large demand on their time and energy (Lindgren et al., 2016). If parents were having difficulty answering the question, a prompt was used: "Have you considered things such as quality, frequency of attendance, and/or inclusion in activities?"

Have you experienced any changes in your marital and/or intimate relationships since your son or daughter was diagnosed and, if so, can you describe these changes?

Marriages have been found to experience both strains and improvements over time, with some parents stating that their relationship has improved over time, as their partner was their primary source of support throughout (Long & Marsland, 2011). Although closeness seemed to be strengthened, intimate and sexual relationships have been found to deteriorate for parents of young children with cancer (Lavee & Mey-Dan, 2003; Machado da Silva et al., 2010). It was important to see if the same trend existed for parents of EA children, specifically if the parent was dependent on a spouse for support. If parents had difficulty answering this question, a prompt was used: "Have you considered aspects such as sexual desire, fulfillment and engagement, and intimate communication?"

What support, if any, have you received during this experience? Grinyer and Thomas (2001) found that support is less likely to be offered to parents when their child is not a pediatric patient. Considering this, it was important to ask parents if they had received any supports during their experience and, if they had, what these support sources

were. If parents had difficulty answering the question, a prompt was used: “What types of support have you received (for example, emotional, financial, help with household tasks).”

What support do you think would have helped you during this experience? Parents who are caregivers to children with chronic illness or disease have been found to experience less caregiving burden when they have social support, whether it is actual or perceived (Edge Schoeder & Remer, 2007; Lovell & Wetherell, 2012; Rodakowski et al., 2012; Shieh, Tung, & Liang, 2012). It has been noted that parents of older children tend not to receive the same amount of support as parents of younger children (Grinyer & Thomas, 2001). I wanted to know what types of support parents believed would have been beneficial to them, given their unique set of circumstances. If parents had difficulty answering this question, a prompt was used: “Why do you believe that these supports were not readily available to you? Why do believe that you would have benefitted?” Parents in the study responded with their need for informational support; therefore, a specific prompt about this type of support was not given.

What advice would you give to parents going through a similar situation? Having been through the experience, it was interesting to see whether or not participants had advice for those about to thrust into a similar journey, and what that advice entailed. Such questions can be considered “indirect” (Kvale & Brinkman, 2009) which can help to give additional genuine insight into the participant’s experience but can also help tap the participant’s knowledge of similar others. Morse (2000, p. 4) refers to such questions as providing “shadowed data” and are very important for enriching the data, reducing the number of participants needed.

After the semi-structured questions had been asked and answered, the participant was invited to share any additional information they felt would be helpful to the study.

Additional documentation. Participants were asked to supply the study with additional documentation that would help enrich the context of their case. Documentation is a useful source of evidence for case studies as it is used as a way to augment and corroborate the information found from other evidence sources in this case, interviews (Yin, 2013). Ideas for document examples given to participants included photographs, blog and/or journal entries, medical journals, and videos. Participants were also welcome to send documents that were not included in the list of examples, but that they felt would be helpful to the study.

Informed consent. The process of informed consent was done through email. When participants sent an email to the study's email address expressing interest in participating in the study, I replied with the option for the participants to complete the informed consent (Appendix F). The email included two forms of the informed consent: (1) informed consent included in the body of the email, where participants typed "yes" or "no" to questions outlined and type their name as their signature; and (2) as a fillable Microsoft Word document. Including the informed consent in the body of the email ensured that participants who had blocked attachments would still receive the informed consent. It was possible that some participants would prefer a fillable form which they could print out easily and have for their records, therefore a fillable Microsoft Word version of the informed consent was also included. Participants were requested to indicate whether or not they wished to receive an email with the dissemination of the study's results at the completion of the thesis, and whether they were open to future

contact by the researcher regarding clarification of their interview responses or the documentation that they provided.

The two participants who took part in the online focus group were asked if they would like to take part in the case study methodology, and be asked a few more questions, as well as supply documentation. Both participants were provided with a new informed consent form which they were requested to complete prior to continuing with the study.

Compensation. There are issues with compensation in regards to ethics, unfairness, and informed consent (Grady, 2001; Grant & Sugarman, 2004; Wertheimer & Miller, 2008). Dresser (2001) argues that advertisements which emphasize compensation above all else can create a problem whereby participants are motivated by the monetary reward rather than contributing to knowledge. This is one of the reasons that, although compensation was offered to participants in this study, it was not for personal monetary gain and, though mentioned, it was not prominently displayed on advertisements for the study. In lieu of personal monetary compensation, it was decided that participants could enter a cancer-related organization or support group, or a cancer ward within a hospital, into the draw for a donation of \$100. The participant was given the opportunity to provide the name of the organization/group/ward and its location at the interview should they have wished to enter the compensation draw. A random draw was made at the end of the study and participants received an email to notify them which organization/group/ward received the donation. This draw was done by writing the names of the three organizations on slips of paper, placing the pieces of paper in a basket, and

having a third party draw the winning organization. The donation was made on behalf of the study to reduce the potential for individual participants being identified.

Procedure. Once ethical approval was granted from the Dalhousie University Research Ethics Board, recruitment of participants began. After low enrollment and recruitment issues, an ethics amendment was submitted and approved in order to change the methodology. After the amendment was approved, two existing participants were asked if they would like to continue with the study, given the change, and, if so, if they would like to add more context to their experience. Other potential participants who had emailed prior to the change but had decided not to participate in the original study, were emailed to ask if they would now be interested. The third participant emailed the study following the change after seeing an older advertisement. After being notified that the method had changed, the participant chose to take part.

Data collection occurred as participants registered. Once an interested participant contacted me, I sent her an informed consent form (Appendix F). When the informed consent was returned, completed and signed, an interview time and medium was chosen. Participants were invited to scan and email additional documentation or mail documents. Participants were instructed that, should they be uncomfortable with any of the questions I posed, they were not required to answer the question and we would move on to the next question.

Once all data had been collected, an email was sent to each participant. This email included a debrief (Appendix G), a list of organizations for support (Appendix H), and a helpful tip sheet (Appendix I).

Data Management and Analysis

Data were hand-coded and analyzed using thematic analysis.

Data management. For the majority, data was first received electronically. This data was saved under specific participant files on my personal laptop. Telephone and in-person interviews were recorded via a hand-held recorder and handwritten notes were taken. Table 1 highlights the different types of interviews used for each participant. Sandra's interview was conducted via email and the previous discussion forum, with several back-and-forth emails to clarify specific responses. Laura's interview was a combination of submitted responses to the discussion forum, and in-person. During the in-person portion, I was able to clarify responses from the discussion forum, and ask some further questions to get a better understanding of the participant's overall experience. Melanie's interview was conducted over the phone. Interview recordings were given to a transcriptionist to be transcribed; these transcriptions were then emailed to the study's Dalhousie email address. Non-meaningful sounds, such as "um" or "ah", were removed. Emailed transcriptions were then saved electronically and filed under the participant-specific files. Hard copies of all data were printed for easy analysis and hand-coding. The decision to code by hand was made so I, as the researcher, could have a better understanding of each case. Hand-coding was done by writing down notes, including potential codes and themes, on the hard copies of the documents for each participant. Originally, a data analysis software program, was to be used to help structure the data and assist in coding. A decision was made hand-code as computer-assisted coding can be confining, as researchers can, perhaps unconsciously, allow the software to drive the coding process, rather than allowing the codes to emerge from the data (Klenke,

2008). With only a few cases, it was possible to hand code. Had there been many cases, it would have been necessary to look at alternatives. As I was adhering to an inductive coding approach, it was important that the codes came from the data, rather than predefined notions. Hand-coding allowed me to stay engrossed in my data, and to understand the conceptual contexts within the documents. Thematic analysis was applied to all documents, such as transcribed interviews, blogs, and personal medical journals. Photographs were used as a source of visual data, and were analyzed by identifying themes which constructed the experience of each participant's case. The mothers who shared photographs were asked for information about the image, in order to gain a better understanding of the constructs within the photos.

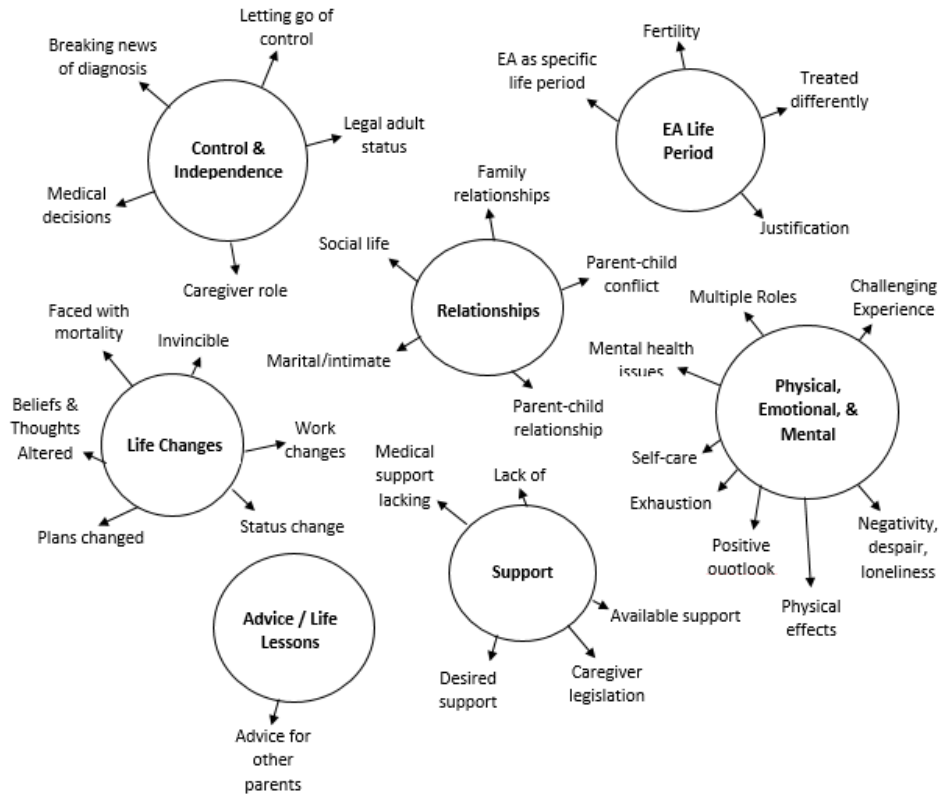
Analysis technique. Thematic analysis is well suited for interview study designs (Joffe, 2012). Themes identify meaning patterns within the qualitative data (Willig, 2013). Thematic analysis is generally done in a sequenced, step-by-step process (Braun & Clarke, 2006; Joffe). The analysis for this study followed the guidelines set by Braun and Clark and consisted of six phases.

Phase 1: Familiarizing yourself with the data. Braun and Clarke (2006) emphasize the importance of the researcher becoming familiar with and understanding his or her data. It is recommended that the researcher read and re-read the data to become fully engaged and familiar with what it contains. The researcher can also start jotting down ideas for rough codes. After reading the interview transcripts and reviewing the documentation for each case study once, I began to produce rough codes during the second review.

Phase 2: Generating initial codes. Phase two begins once the researcher has familiarized him/herself with the data and includes creating an initial list of codes (i.e. a coding frame). A code is essentially a label that highlights a unit of meaning that is important to the study (MacPherson & McKie, 2010). They are “the most basic segment, or element, or the raw data or information that can be assessed in a meaningful way regarding the phenomenon” (Boyatzis, 1998, p. 63). I coded data using an inductive approach, which is not informed by pre-existing theoretical assumptions, and is instead informed by the data (Willig, 2013), noting items of importance and/or interest (MacPherson & McKie). After I had reviewed the interview transcripts and documentation for each case three times, I created a coding sheet and produced 36 initial codes. These codes were then reviewed by my supervisor and I and some were merged to reduce the number of codes.

Phase 3: Searching for themes. Phase three occurs when all the data have been initially coded and involves searching for themes within the data. By the end of the phase, a list of potential themes should exist, including sub-themes and all data should have been coded in relation to them. When the codes had been reviewed and some had been merged together, a thematic diagram was created to visually depict the themes that had emerged. This thematic diagram was an evolving diagram, which began while I was generating initial codes and continued until I was ready to produce the report. Each version of the diagram was hand-drawn. Figure 1 shows the first version of the diagram, following the completion of phase 2.

Figure 1: First Phase of Thematic Diagram



Phase 4: Reviewing themes. Once the researcher has created a list of potential themes, they are then reviewed to discard those that are not relevant or those that could be grouped together. Other themes may need to be broken down as there could be more than one theme within the original. When I had selected an initial set of themes, I reviewed these with my supervisor and, upon review, discarded irrelevant themes and began to group others together. This was done through in-person meetings with my supervisor where we went over my coding document and hand-drawn thematic diagrams, and discussed how the codes and themes worked together, and which ones were sub-themes versus those which stood on their own.

Phase 5: Defining and naming themes. Once the researcher has decided on a list of final themes, he or she must define and name the themes to depict exactly what each theme is meant to capture. I originally named themes based on the overarching concept contained within each theme. Upon review with my thesis committee, themes were then renamed to convey the essence of what was going on within that theme, as described by the participants.

Phase 6: Producing the report. Once all themes were defined and named, the final report of the study was completed. I began writing the report as I reviewed the themes, and completed the final report after all of the themes were defined and named to accurately capture the essence of the subject matter.

Quality and rigour. Qualitative case study research tends to be viewed as the less rigorous of available types of research, and specifically when compared to those quantitative in nature. One reason for this is that qualitative researchers sometimes do not provide as much detail about methodology and results, yet this is necessary for the researcher to demonstrate rigour and credibility (Hyett, Kenny, & Dickson-Swift, 2014). Hyett and colleagues critically analyzed methodological descriptions of 34 published case studies in order to develop a list of criteria for assessing the rigour of case study research. The checklist included: (1) is the case adequately defined; (2) is there a sense of story to the presentation; (3) is the reader provided some vicarious experience; (4) has adequate attention been paid to various contexts; (5) were data sources well-chosen and in sufficient number; (6) do observations and interpretations appear to have been triangulated; (7) is the role and point of view of the researcher apparent; (8) is empathy shown for all sides; and (9) are personal intentions examined.

The collective case in this study has been adequately defined as parents of EA children with cancer. Each case within the study allows for an examination of the similarities and differences between three parents' experiences, which informs the overall study. It was my intention to ensure that the reader was presented with both a sense of story and some vicarious experiences while reading the case study report. I wanted to ensure that the reader understands that the collective cases are meant to highlight the experiences of three mothers, and have readers be able to feel a connection to the challenges that these mothers faced, as well as the positive aspects that arose from their experiences. There were various contexts experienced by the three mothers who participated in this collective case study, and the three different contexts are explained in detail. The three cases included a mother of a daughter who survived cancer, a single mother of a son who survived cancer, and a mother of a daughter who died from cancer. The emotional story of the mother whose daughter died was evident in her interview and the documentation that she provided. I believe that readers are able to feel empathy for her experience, and the pain that she had to endure. Data sources were chosen based on participant comfort and availability. There were differing data sources used including interviews, medical journals, photographs, a speech, and a blog.

Triangulation is a common procedure to ensure trustworthiness in case studies by corroborating evidence from the participants, types of data, and methods of data collection (Creswell, 2014). The multiple sources of data for each participant allowed me to explore different ways in which the experience was understood by each mother, as well as the differences between the mothers. Baxter and Jack (2008) explain that a collective case study allows "the researcher to analyze within each setting and across

settings” (p. 550) in order “to understand the similarities and differences between the cases” (p. 550). For triangulation within each case, the different data sources provided by each participant were examined to see if they inherently provided the same understanding of the participant’s experience. For example, the information that one mother provided during her interview about her daughter’s independent nature was evident in a picture of her daughter in a dress that her daughter had been adamant that she, herself, sew for prom, as well as in a speech the mother gave that highlighted her daughter’s independence. Where two sources of data provide the same or very similar information, as here, only one source is mentioned within the results section. Across cases, triangulation occurred by looking at the responses given through interviews and other data sources. An example of where triangulation highlighted similarity between cases is the participants’ need for support that they found was lacking.

I have attempted, as the researcher, to explain my role and point of views throughout the report. Throughout data collection, I myself was an EA. As an EA, I have worked and volunteered with cancer organizations and have heard many stories from both the patients and their family and friends. I am an independent EA prone to sharing control with my own parents as I navigate my developmental stage. For some things, I still lean on my parents for their support and guidance, while for other decisions, I can experience frustration if they try to get involved. For this reason, I can understand the potential conflict that would exist in a normal day-to-day relationship between mother and EA child, and can acknowledge that this would likely be heightened by the traumatic experience of cancer. Cancer can be a terrifying experience, both for the child and the parent, and I think that trying to work together through can take tremendous effort. I had

a great deal of empathy for the participants as individuals who have experienced a difficult situation, as well as research participants who spoke of their experience to a stranger. I was also empathetic to the way that readers, both academics and non-academics, would understand and conceptualize my report, as well as my feelings and understandings as both a researcher and an individual. Finally, I believe that I have adequately portrayed personal intentions for both myself as the researcher and for my participants for choosing to take part in this study.

In addition to the criteria set by Hyett and colleagues (2014), I also worked to establish and maintain quality and rigour through adhering to strategies determined by Creswell (2014). These included using rich, thick descriptions and presenting negative/discrepant information which counters themes. Rich, thick descriptions enable readers to feel as though they have immersed themselves in the situation that the researcher is describing (Creswell). To do this, I used quotations from participants to emphasize specific issues that these parents face. Providing negative/discrepant information refers to the discussion of information that is contradictory to the majority of the findings (Creswell). I provided any information that was not in line with my themes, as it showed that not all participants had exactly the same experience. For example, in regards to informal support, two mothers found that it was readily available, while another mother found that it was lacking.

Patton (2002) described qualitative research as “time consuming, intimate, and intense” (p. 35). Experts in the field of qualitative research have recommended that writing notes to oneself during research has benefits, including discovering thoughts that the researcher did not know they had (Glesne & Peshkin, 1992; Maxwell, 2005).

Reflexive journaling can also provide insight into a researcher's biases, thoughts, and feelings which can better inform the reader (Watt, 2007), and provides the researcher with something to go back to when considering the outcomes and conclusions of the study (Ortlipp, 2008). I engaged in reflexive journaling throughout the entire research process, including design, data collection, analysis, and the initial writing of the report. Throughout the experience I found that I empathized greatly with the participants' experiences, and at times had to step away from the data to take a break both mentally and emotionally. Some of my reflections are evident in the results section.

To confirm inter-coder consistency, a reliability check is recommended whereby others are requested to look over the existing coding frame and a sample of transcriptions to confirm that they came up with and agreed upon the same codes as the researcher (Patton, 2014). This was done by requesting my lead supervisor as well as an outside party to look over my coding frame and a transcription sample. The lead supervisor and thesis committee provided feedback during my pre-defence meeting to ensure that fresh perspectives were sought and themes were adequately described, conceptualized, and named.

Role of the Researcher

As the researcher, I was actively engaged in the recruitment of participants, and in the creation and implementation of the study design, including the interview guide. I also engaged in reflexive journaling, as noted previously. As Malterud (2001) states, "a researcher's background and position will affect what they choose to investigate, the angle of the investigation, the methods judged most appropriate for this purpose, the findings considered most appropriate, and the framing and communication of

conclusions” (p. 483-484). As such, it was important to take into consideration my motives, background, and perspectives to ensure that these were adequately handled and were working for the study, not against it (Malterud).

My reflexive journaling allowed me to not only understand my preconceptions and motives, but also my experience during the research process. I journaled after each interview that I conducted, and found that I had difficulty conceptualizing the role of the researcher as the interviewer. As a result of reading the transcription of my first interview, I attempted during subsequent interviews to ensure that I increased my outward display of empathy and understanding, as well as working to receive the detailed information that I sought. As I was employed at a breast cancer non-profit during the time of data collection, I was accustomed to hearing patient stories and providing a listening ear, but not to do so while also seeking detailed information for a specific purpose. I also journaled when I had emotional experiences, or felt confusion and/or surprise, or was intrigued by the data. For example, after reading one particularly sensitive piece of data, which was the first item of data I had read, I realized how difficult these situations must have been for my participants, and I had a higher degree of understanding of what may be going on underneath the surface.

Ethical Considerations

Ethical approval was sought and gained from the Research Ethics Board at Dalhousie University in Halifax, Nova Scotia, Canada.

General ethical considerations. In accordance with the Dalhousie Health Sciences Research Ethics Board, all written data were stored in a locked area, and computer files were stored on my personal computer and external hard drive, as backup

files, and were password-protected. At the completion of the study, data were given as an electronic version on a flash drive to the lead supervisor, Dr. Lynne Robinson, to keep secure for five years. Participants were given the opportunity to receive an email with highlights of the group results from the study.

Specific ethical considerations. The focus of this study was on a population that could be perceived as vulnerable in the sense that they may be emotionally compromised as a result of their experience. Cancer in itself is a sensitive topic and all participants had a child who had been diagnosed with this disease. There was also participation from one mother whose daughter had died. Dyregrov (2004) studied the experience of parents who had lost a child and had taken part in research regarding this loss. The study included in-depth interviews with 64 parents from 37 families who had lost a child/young adult to suicide. All of the parents reported that the research participation had been positive, and the majority indicated that having the opportunity to talk about their child and their loss was important. That is not to say that speaking of loss is not without its issues. Dyregrov found that 73% of the parents reported that the interview was slightly painful. None of the participants, however, regretted participating and 94% of them said they would recommend it to a friend in a similar situation. To protect against potential negative effects of participating in the study, a comprehensive listing of support groups and organizations (Appendix H), as well as a helpful tip sheet (Appendix I), was emailed to all participants.

There was also the concern that participants would need to feel comfortable that their information would remain anonymous and confidential. This is especially important in a study with only three participants. All three participants were given details on how

their information would be utilized and stored, both in the informed consent as well as prior to commencement of the interview and when requesting any additional documentation. Participant information was only accessed by myself as the lead researcher, as well as the lead supervisor. Any additional documentation that participants provided was used only in analysis and, other than quotations, none of these documents were published in the final report. Furthermore, email addresses of participants were only accessed by myself as the lead researcher. Email correspondence was through a Dalhousie University email created specifically for the study, and emails were sent individually, including debriefs and dissemination.

Use of data in dissemination. Demographic information was collected from each individual participant, and was provided in the thesis, although any identifiable information was excluded. As part of the informed consent, participants were made aware that the researcher may use direct quotations from them in reports of the study, unless the participant explicitly stated on the informed consent that she did not wish to be quoted in the study report. Participants were able to take part in the study even if they did not wish their quotes to be used, however, no participants requested that their quotes not be used. Quotations used in the study report were coded by pseudonym only, without identifying information.

Dissemination Plan

Participants who acknowledged that they wished to know of the study's outcome were sent an email at the conclusion of the study, after the final report was complete, with the highlights of the overall group outcomes. No individual results were given.

Academic. Results from this study were presented to my thesis committee, an external reviewer, and interested professors and students at Dalhousie University during my thesis defense. This study was also presented at the 2016 Canadian Association of Psychology Conference, “Generation Y to Older Adults: Psychosocial Care Across the Ages” in Halifax, Nova Scotia. It is also my intent to present my findings at the Crossroads Interdisciplinary Health Conference, hosted by the School of Health and Human Performance at Dalhousie University, in 2017. Results will also be submitted for publication in academic journals, as well as potentially in open-access journals.

Community. As a way of informing the community, I will review ways in which I can inform health professionals who may work closely with parents in similar situations, as well as related cancer organizations. Knowledge will be translated through research summaries emailed to cancer organizations throughout Canada. The feasibility of publishing a summary of the findings and its implications on Cancer View, a web portal designed to connect Canadians (i.e. general population, practitioners, and researchers) to cancer information and resources, will be examined.

Knowledge Exchange

Through the study, I engaged in some knowledge exchange with the participants. Questions regarding the types of support perceived as beneficial and what support was lacking, as well as advice to other parents in similar situations were asked. The answers to these questions will help inform further research and interventions with this population.

As mentioned previously, traditional knowledge exchange will be carried out through the submission of the study’s findings for publication in a peer-reviewed journal.

There will also be a short media release created and sent to cancer organizations that may work with these populations, and health promotion organizations (e.g. Health Promotion Ontario). This will allow the information to be shared widely among members of these organizations. It would be ideal if there could be media coverage in newspapers which allow for community publications.

Chapter 3: Results

The purpose of this study was to understand how parents of EA children with cancer were affected as a result of their experience. The first research question was: how does having an emerging adult child with cancer affect the parent psychosocially? This question concerned how having an EA child with cancer affected the parent psychosocially. The results of this study highlight the psychosocial challenges that parents of EA children with cancer face, including increased stress, anxiety and worry, a struggle with balancing control of their child and their child's independence as an EA, vocational changes, and a decrease in social engagement. Positive results were found, such as a (1) strengthening of the parent-child relationship, (2) a greater sense of empathy and understanding for others, and (3) an increased ability to be positive about life in general. The participants' experiences also highlighted the feelings that they had about being different than other parents of children with cancer, because their children were in a developmental life phase that did not fit in to the cancer care continuum.

The second research question was: what support is important to parents of emerging adults with cancer? This question concerned what support is important to parents of EA children with cancer. It was found that all three mothers believed that support from family, friends, and the community was important. Despite this, one of the mothers did not feel as though she had reliable and readily available informal support. All three participants explained that they would like to see formal support groups for parents of EA children with cancer, in order for them to share their experiences with individuals with similar experiences.

Cases

Three participants volunteered to take part in the study; each participant represents an individual case. The following table depicts the demographic information for the participants.

Table 3

Demographic Information

	<u>Sandra</u>	<u>Laura</u>	<u>Melanie</u>
Sex	Female	Female	Female
Relationship to Child	Mother	Mother	Mother
Ethnicity	Caucasian	Caucasian	Caucasian
Age Range	40-49	50-59	50-59
Relationship Status	Common-Law at diagnosis, married during data collection. Self-identified as single and was single for much of the time she spent raising her child	Married	Married
Child's Sex	Male	Female	Female
Child's Age at Diagnosis	19	18	23
Child's Living Situation at Diagnosis	Away at university full-time	Away at university full-time	Away at university full-time
Child's Living Situation After Diagnosis	Returned home full-time	Returned home full-time. Returned to university full-time after treatment	Returned home full-time
Did Child Survive Cancer?	Yes	Yes	No

All three participants identified as female and as the mother of their child. Two participants were mothers of daughters who had been diagnosed with cancer, while one participant was the mother of a son diagnosed with cancer. The average age of the participants at the time of their interviews was 50.6 years. One participant, Sandra, was

younger than the other two mothers in this study. This could mean that she potentially gave birth to her son during her emerging adult phase, which could have impacted how she handled her experience. Parenting behaviours have been found to be different among EA mothers and adult mothers. For example, although EA mothers use cognitive stimulation with their children, they do it less than adult mothers; they are also more likely to use punishment techniques such as spanking and time-out (Lewin, Mitchell, & Ronzio, 2013). EA mothers also report less father influence than adult mothers. All participants were Caucasian and represented three provinces within Canada. Two participants were married at the time of their child's diagnosis and at the time of their interview. One participant was in a long-term common-law relationship at the time of diagnosis and married during data collection.

The average age of the children at time of diagnosis was 19.6 years. All three of the children lived away from home at time of diagnosis to attend school and returned home following their diagnosis for treatment. Of the three children, one died from cancer. All three children were diagnosed with different types and stages of cancer and, at the time of the interview, the remaining two children were not currently in active or palliative treatment.

In total, six participants expressed interest in the study by emailing me via the study's email. Of these six, two did not respond to further attempts to contact them, and one participant decided that she did not have enough time to give to the study.

Pseudonyms were assigned to participants to maintain confidentiality and anonymity, as well as to allow readers to feel a connection with the participant as they read the report, rather than using participant numbers. Quotations were used without

alteration except for non-verbal utterances and sounds. Brackets were used to indicate where potentially identifiable information was removed from the quotation.

Case one: Sandra. Sandra is a Caucasian woman in her 40's whose son was diagnosed with cancer. At the time of her son's diagnosis, Sandra worked at a high-level executive job and had recently moved in with her common-law partner. Throughout her son's childhood, Sandra had been a single mother and had handled multiple roles in the care for her son. Her son had also been diagnosed with Type 1 diabetes as a child and, as a result, she was accustomed to being in the caregiving role for a chronic disease.

Sandra's son was diagnosed with cancer after a mass was found. Sandra had difficulty convincing the healthcare system to perform a biopsy. Once the biopsy was conducted and the results given, a cancer diagnosis was confirmed. Her son underwent chemotherapy treatments which ended approximately 1.5 years prior to Sandra becoming involved with this study. During her son's treatment, Sandra made accommodations with her employer to work full-time from home and the hospital, but eventually lost her job prior to her son finishing his chemotherapy treatments. Although the reasoning behind her being let go from her job was the elimination of the position from the company, Sandra feels that it was as a result of the changes she had to make to her work hours, as someone else was hired in the same position afterward. In addition, Sandra experienced very little support from family and friends during her journey. She dealt with high levels of stress which led to multiple miscarriages. Her son had moved out when he was 18 to attend university in a different city. Following his cancer diagnosis at the age of 19, he moved back home for treatment. Her son struggled with depression during his treatment and, although he attempted to return to university following his treatment, he was unable

to cope and returned to live with Sandra full-time where he currently resided at the time of data collection. Sandra married her common-law partner during data collection and is currently living with her husband and son. She is now working again. Data collected from Sandra included an interview that was conducted both through the online discussion forum and through email, photographs of her son, and a medical journal where she detailed the medications and treatment her son endured.

Case two: Laura. Laura is a Caucasian woman in her 50's whose daughter was diagnosed with cancer. Laura lives in a large Canadian city and is married. Her family structure includes her husband, a daughter who was diagnosed with cancer, and a teenage son. At the time of her daughter's diagnosis, her son had just been diagnosed with a non-chronic medical condition which meant that both children were undergoing medical treatment and experiencing restrictions on their independence. Laura's son was not an EA at the time. Laura's daughter was away attending university in a different province when she was diagnosed at the age of 18 during a trip home. Laura's daughter moved home during treatment, although she still managed to complete her schooling for the year. During her treatment, Laura's daughter held a part-time job as well as participated in sports, until she was required to leave the team due to medical risks. Although Laura and her husband wanted their daughter to rest, Laura said she believed that the way her daughter acted was how her daughter coped with her illness. After treatment ended, which was approximately 2.5 years prior to Laura becoming involved in this study, her daughter returned to university where she remained. Four months after returning to full-time university studies, Laura's daughter suffered an emotional and mental breakdown, which Laura believed was a result of her daughter not effectively coping and processing

her feelings during her cancer experience. Laura and her family worked through this breakdown together, her daughter successfully returned to school and has since graduated with her degree. It is unclear whether professional support was sought for the breakdown.

At the time of her daughter's diagnosis, Laura worked full-time. After using all of her sick days and vacation time, Laura opted to switch to part-time in order to attend her daughter's medical appointments with her and to be more available. During the cancer experience, Laura had access to support through family, friends, and the community.

Part of the experience Laura had included her daughter's decisions of whether or not to freeze her eggs for fertility preservation, as there was a chance that the chemotherapy would reduce the possibility of her daughter being able to conceive in the future. Data collected from Laura included an interview conducted partially online through the focus group as well as in person, a speech that she gave at a cancer-related function, photographs, and a medical journal where she kept a record of her daughter's appointments, medication, and general information about cancer and its treatment.

Case three: Melanie. Melanie is a Caucasian female in her 50's who lives in a large Canadian city. Her daughter was diagnosed with a rare type of cancer at the age of 23. Her cancer experience spanned five years, eventually leading to her death at the age of 28. At the time of her diagnosis at the age of 23, Melanie's daughter lived away from home to attend university. She had been living away from home for several years. Following her diagnosis, she returned home, and left again after treatment was completed. She returned home again when complications arose, and remained living full-time with her family until her death, although she did spend a short time in hospice care. When active treatment ended and it was clear that her daughter did not have much longer

to live, the medical care team decided to move her from hospital care to the hospice. As a result of her daughter feeling uncomfortable as one of the youngest patients in the hospice, and not wanting to see people die every day, the staff allowed her to go home and keep her bed in the hospice in case she had a medical crisis. The family structure included her husband, her daughter who died from cancer, and a son. Palliative treatment ended and her daughter's death occurred a few weeks prior to Melanie becoming involved in the study. Melanie explained that her family relationships were strong, and that she had a good relationship with her daughter that only strengthened as a result of the cancer experience. During the experience, Melanie worked until the last few months of her daughter's life, when she took a leave of absence. Melanie had access to a strong support system during her journey. Data collected from Melanie included an interview conducted over the phone, and a blog. The majority of the blog was written by Melanie, although her daughter did contribute some posts. The blog was a way for Melanie to let others know of her daughter's progress and to share her thoughts and feelings.

Findings

Through the collection of photographs, journals, and a blog, as well as interviews with each participant, five themes emerged surrounding parents' psychosocial experiences when an EA child has cancer: (1) Lost world; (2) He/she is an adult, but I'm having difficulty letting go; (3) Walking on egg shells; (4) Your whole world is changed; (5) We wish we could share our experiences.

Table 4

Outline of Themes

<u>Theme</u>	<u>Relevant Sub-Themes</u>
Theme 1: Lost World	The healthcare system does not understand I'm not being heard
Theme 2: He/She is an Adult, but I'm Having Difficulty Letting Go	Parent-child relationship Strengthening the relationship
Theme 3: Walking on Egg Shells	Days filled with stress Self-care
Theme 4: Your Whole World is Changed	We are no longer the same Work and social life changes
Theme 5: Being Supportive of Each Other	N/A

Theme one: Lost world. One theme that emerged through the analysis of the mothers' interviews and documentation was that each mother felt that she, and her experience, was not fully understood by their friends, family, and the healthcare system, in large part because of the developmental life phase which their child was in. Melanie described the experience of an EA with cancer as *“between the ages of probably 18 and I would say even like 25, if you have cancer you're kind of in this lost world.”* Sandra wanted to care for her EA son through his cancer journey, just as she had been providing medical care for him throughout his life for an unrelated chronic illness. She noted, however, that as a result of her son being a legal adult, she had to struggle with the healthcare system to be allowed to provide a certain level of care for him and be involved in the process.

The healthcare system does not understand. The mothers commented that they felt as though their children were treated differently during the cancer experience as a

result of their age. Despite her daughter being diagnosed with cancer, Melanie felt that her child was treated as healthy because she was young: *“it was so unbelievable that she was so sick that she got treated like she wasn’t as sick as everyone else.”* Melanie found that *“a real challenge for us, is finding the proper acceptance of what she was going through from the medical community.”* Melanie’s daughter was frequently told that she looked healthy, and that she was young so she had better prospects than the older patients. In reality, Melanie’s daughter was terminally ill and the comments made by the healthcare personnel caused frustration for both Melanie and her daughter. Sandra faced a similar issue, as she felt that the medical personnel did not take the mass that was found in her son’s neck seriously enough; she felt that it took an undue amount of time to have the tests ordered and the diagnosis given. Looking back on the experience, Sandra commented that *“not having to fight with all health care workers to initially have the massive lump on his [body part] biopsied”* would have helped make the experience easier, especially at the beginning when there was such a high degree of uncertainty. Unfortunately, Sandra still feels that, if she had not been in her previous employment position, the biopsy would have taken longer to happen: *“the only way I was able to advocate so strongly for him and get him diagnosed and into treatment is because I’m a [career title] and medical practitioners tend to avoid run-ins with [career title].”*

Melanie specifically highlighted her belief that younger children are better cared for in the healthcare system than emerging adults. Given the research to date, and my own experience as an EA seeking medical treatment for chronic illnesses which are unrelated to cancer, I found that I could understand Melanie’s feeling that EAs do not necessarily receive the same level of care as younger children. This is unlikely resulting

from a lack of care from the healthcare system, but rather a lack of understanding. Once an individual reaches the age of 18 and outgrows pediatric care, the healthcare system seems to lump him/her in with the remainder of the population, and does not necessarily pay attention to the specific issues that could arise as a result of their life phase. Melanie felt as though the care her daughter received was inappropriate given her age. Her daughter was consistently placed in hospital rooms with much older patients, as she was too old for the pediatric ward. At one point, her daughter shared a room with four elderly men. Medical care seems to be framed by simpler development stages, such as pediatric and adult, and there is relatively little space or understanding of the in between stage of emerging adulthood. As a result, no recognition is given that EAs are too young to be part of the older cancer patient group, and too old to be given pediatric status. Within the EA developmental life stage, parents can still be involved when cancer is present, although not like they would be if their children were pediatric patients. Although their children are more independent than they would be if they were in the pediatric grouping, they are still young, and still sick with a potentially life-threatening illness. Situations such as this could make both the EA child and his/her parent(s) uncomfortable, thus increasing their stress during an already difficult time. As Melanie spoke, her exasperation was palpable as she discussed the inappropriate place of care provided for her daughter. Relevant literature was also found to be lacking; Melanie found that she could not find any information that related to EA children with cancer, or their parents. As a result, she felt as though healthcare professionals do not necessarily consider the needs of parents of EA children with cancer:

I was looking through one book and there was no one that was a young adult, and if there was any reference to a young adult, it was a young adult taking care of their parent going through cancer, or taking care of a child going through cancer, there's nothing for parents of young adults.

In addition, she felt as though pre-judgements were made about her child because of her child's age, many of which were inaccurate or assumptions. One such assumption was that parents are not involved in the care of their children once they legally become adults. All three mothers in this study were actively involved in their child's care. Melanie commented: *"it's assumed that if you're a certain age, if you're over 25 maybe, then you're married or have a significant person that's taking care of you; that it's a couple thing."* Melanie's daughter was 23 when diagnosed and passed away from cancer at the age of 28.

I'm not being heard. All three of the mothers in this study experienced different cancer diagnoses in their children. They all, however, shared in the struggle to justify their feelings and emotions surrounding the experience of having their EA child diagnosed with cancer. As mentioned previously, Sandra felt as though she had to justify her fear of a potential life-threatening disease in her son when she fought to have an abnormal lump biopsied.

Laura *"wanted to shout from the rooftops that my daughter had cancer."* Laura's daughter was diagnosed with a cancer which has a high treatment success rate. As a result, Laura found herself struggling to justify to herself that it was still cancer and she had a right to be upset about it. Despite the high success rate, Laura could not help thinking that there was still a percentage of cases that are not successfully cured, and her daughter could still fall into that percentage. This led to an inner struggle for Laura as she fought to come to terms with what she was feeling versus what the outside world was

conveying: *“I kind of maybe in my mind thought it was worse than it was, I don’t know, it seemed like a bigger deal to me. And maybe that was just ‘cause it’s your kid right.”*

During her interview, there was palpable frustration and confusion emanating from Laura as she spoke about justifying her feelings, including her worry and free. She expressed how she could not understand why those outside of the immediate situation were not taking her daughter’s cancer diagnosis seriously. She was scared for her daughter, and she could not fathom why people were telling her that she did not need to be.

Melanie’s daughter was diagnosed with a type of cancer that is not common in young adults, and she eventually died from it. Although her daughter’s cancer went into remission following treatment, involving an amputation, it metastasized two years later. Despite this, the healthcare team originally believed the cancer to be treatable; however, as the cancer journey progressed, it was no longer a case of when the cancer would be cured, but rather how long Melanie’s daughter had left to live. Although her daughter was very sick, she appeared healthy throughout much of her journey. Melanie commented that her daughter had to continuously remind medical personnel that she was sick when they commented about how healthy she appeared. Her daughter felt frequently forced to say *“I’ve got terminal cancer, I’m not healthy.”* For Melanie, the struggle to be heard and understood was real: *“I feel like people think we’re nuts; that we’re exaggerating about how sick she was or the serious nature of her condition. It just proves that what you see doesn’t necessarily reflect what is really going on.”*

When a mother hears the word “cancer” in relation to their child, they are bound to worry. Some cancers have worse prognoses, and others are labelled are “good” cancers. For example, Laura’s daughter’s cancer was one of the so-called good cancers

which has a high survival rate. Whether or not the survival rate is high for the cancer which their child is diagnosed with, cancer is still a terrifying concept and difficult to come to terms with. Other people, whether they be health care personnel, friends, family, or the general public, may not take the cancer diagnosis in an EA as seriously as the mother would. This could be because they do not understand EA cancer, as it is not widely researched nor discussed, or because they are under the assumption that because the EA is young, and appears healthy, that they can surely beat the cancer and live a long, healthy life. Mothers, alongside their children, can understand the very real struggle for survival in EA cancer, can fear the loss of their children, and can empathize with their children's fears. Struggling to be heard and understood can take away from the attention required when dealing with the parent's EA child, and could take strength away from the parent. The challenge to be understood within the transitional context of emerging adulthood during a cancer experience could add additional stress to the parent-child bond during the cancer journey, as the parent struggles between balancing caregiving and allowing his/her EA child to manage their own care.

Theme two: He/she is an adult, but I'm having difficulty letting go. Trying to balance the control they exerted and attempted to enforce, with the independence of their EA child seemed to be an issue for all of the mothers. The mothers who had daughters reported relatively uncomplicated relationships, but Sandra reported a more complicated relationship with her son. Nonetheless, all of the mothers struggled because their children were legally adults, yet they believed their child to lack the knowledge and life experiences necessary to make proper decisions to deal with his/her cancer. Sandra, specifically, pointed out that had her child have been younger, she would have had legal

control over the medical processes and he would have viewed her as the authority figure. Both Melanie and Laura seemed to have shared control with their daughters, while Sandra's son exuded personal control, and had difficulty when his mother tried to assert her authority. All of the mothers were actively involved in the medical decision-making for their children and all of them, even Sandra, found that they were able to let go of some control of their children and strengthen their relationships.

Parent-child relationship. Both Laura and Melanie strongly verbalized their positive relationships with their daughters, and said they experienced little conflict throughout the cancer journey. These strong relationships were also suggested within the additional documents that both mothers provided to me. Laura provided a photograph of her and her daughter taken shortly after treatment began. Despite the cancer diagnosis and treatment, Laura and her daughter are smiling and appear genuinely happy to be near each other. They are leaning toward one another and their body language is open. I feel as though the support that Laura and her daughter drew from one another is photographed well within this picture. As treatment had commenced, they seemed to have a positive mindset that the cancer would be beat. When I viewed the photo, I felt that the relationship between Laura and her daughter was genuine and strong; the photo emphasized what Laura described to me.

Melanie's daughter contributed to Melanie's blog throughout her cancer journey. This blog chronicled Melanie's daughter's journey, as well as her own. Reading these posts suggested that Melanie and her daughter had a close relationship, as they went on a vacation together without the rest of the family and posted pictures where they are enjoying each other's company and hugging. Melanie's daughter posted a videotaped

interview that an individual had recorded as part of a project he was working on. The suggestion of a strong mother-daughter bond is reinforced as the viewer can watch the interaction between Melanie and her daughter as they spend time together crafting and leaning on one another, both physically and apparently emotionally, through this difficult time.

Although their relationships with their daughters were strong, these mothers also encountered conflict from time-to-time. The mothers, however, felt that any conflicts were handled well and did not disrupt the overall relationship. Laura struggled when her daughter ignored advice given from her parents that she needed to rest. Her daughter's way of coping with the cancer diagnosis was to keep busy, which she did by working part-time and playing in an active sports league through much of her treatment. Although Laura and her husband requested that their daughter rest, she chose to forgo their advice and seemed to downplay the seriousness of the situation. She only quit playing in the league when the risk of harm became obvious. Laura admitted that she and her husband would never be completely sure if their daughter actually did sit out on the games when the risk became too great, as her daughter still went to watch her teammates play. Laura and her husband chose to allow their daughter to maintain the freedom she had prior to her diagnosis, which meant that they did not attend the games with her, and chose to trust her when she said she did not physically participate in the games. This could have been a way for Laura and her husband to resolve a conflict they were experiencing with their daughter. By not restricting their daughter from attending the games, Laura and her husband may have been allowing her the freedom she had before her cancer diagnosis and displaying their trust in her, while also potentially avoiding their own fear that she

could be playing. By avoiding this, they also eliminated the need to deal with that fear and with their daughter if she did play. On the other hand, there is the potential that, by not attending the games with their daughter, Laura and her husband may have, whether consciously or unconsciously, been showing their disapproval of their daughter being involved with the games, even as a spectator. Laura's daughter could have, as a result, interpreted their actions as a lack of support. When sitting with Laura during her in-person interview, I felt that, although Laura was not necessarily completely at peace with her daughter's coping decisions, she had come to understand them. Laura shared a picture of her daughter on the day of her prom; her daughter had made the dress she was wearing, with Laura's assistance. Laura chose to share the picture with me because she said it highlighted her daughter's independence and strong will; she had wanted a hand-made dress and, despite a few challenges, had persevered and worn what she had envisioned to her senior prom. Speaking with Laura, the pride that she felt for her daughter seemed evident to me, and I had the sense that the bond was indeed very strong. She spoke of the prom dress project with slight exasperation, but also seemed to be happy that they had been able to come together and work on the dress together once her daughter had realized it was too much for her to handle on her own.

It appears that Laura's daughter has an independent personality, and chose to cope in her own way, which led to some worry for her mother, and some friction in the relationship. Laura mentioned that, had her daughter been younger, she would have been able to control how much her daughter rested.

Well I guess we were just worried you know...she had a summer job...so she went to work every day, Monday to Thursday...and then every second Friday she would have chemo right so she would, I don't know, go to work, ride her bike to work, then ride her bike to play [sport her daughter played], and then go out with the team after and we were kind of like you need to rest, you need to rest, but she was just determined to go on with her life, so I don't know what emotion you would, I guess that would be worry, you know.

As a child ages, the control a parent has over them diminishes. The parent may not want to seem overbearing, while the child may resist his/her parent's involvement in their illness. For example, a younger child, although apt to voice some annoyance with being told to rest, is still more likely to do as they are told when compared to an EA.

As a result of her son dealing with a chronic illness, suffering from severe depression, and being diagnosed with cancer, Sandra cared for him full-time, emotionally and physically. She also experienced more struggle for control in her relationship with her son than the mothers with daughters seemed to. She noted that, even prior to the cancer diagnosis, she had struggled to maintain a balanced and positive relationship with her son as she filled multiple roles as a single mother. Once her son was diagnosed, Sandra found that she was constantly arguing with her son about topics such as getting enough rest and staying as healthy as possible, as well as medical decision making. Explaining her struggles, Sandra said: *"it is even harder to work that out when he is so ill that he has no control and I am forced to keep control for his safety."* In comparison with the other two mothers, Sandra had been facing her son's potential mortality for the majority of his life prior to the cancer diagnosis, given his other chronic illness. As a result, Sandra may have felt more inclined to try to hold on to the control that she had, as she had been faced with stress and anxiety surrounding her son's health for much longer

than the other two mothers. She felt as though her son resented this because he wanted to remain independent, despite being too ill to do so.

All three of the mothers in the study struggled with the concept that their children were legally adults and could make their own decisions. Laura noted that it was difficult to have her daughter diagnosed with cancer as an EA because, if her daughter had been younger, Laura would have had more control. If her daughter had been an older adult, Laura felt that she would have made more life experience to adequately tackle cancer: *“I think it’s hard when kids are at an age when they are technically adults and want to be independent, but not mature or experienced enough to know that even adults need help and support in certain situations.”* Sandra explained that when children are younger, they are more likely to view their parent as a valuable and knowledgeable resource, rather than believe that they know better than their parent:

There isn’t much I can do to enforce my good intentions, and what I view as the best medical path to recovery, if he won’t accept it. He’s an adult and is legally in charge of his own well-being. This creates a very complicated situation when depression and severe illness make it difficult to care for yourself, coupled with the fact that he is stubborn and is trying to be his own person and anything I say must be wrong.

All of the mothers were actively involved in the medical decision-making for their children. Although they all explained that the final decision was that of their child, they were involved and attended medical appointments. Melanie and Laura found that taking over control of the medical aspect of the cancer journey, or resuming a caregiving role, was a natural occurrence, and they did not report receiving much resistance from their daughters. Melanie explained: *“when she needed the help, she didn’t feel like, you know, we were kind of infringing on her independence or anything.”* Laura also noted that, in

her daughter's case, "*the doctor would explain it and if I agreed with the doctor, I think she was like 'okay, that sounds good'.*" Laura kept a detailed medical journal, which she shared with me. The medical journal highlighted the abundance of information that she, her husband, and her daughter were given during the cancer experience, and all of the treatment appointments that were required. For Melanie, although she, her husband, and her daughter discussed medical decisions together, it was her daughter's decision to choose to stop her treatment. Her daughter wrote a moving blog post about her decision to end her active treatment, from which I include an excerpt:

I have worked hard, I am not a quitter. I am making a choice to live out the rest of my life as happily as possible with the people that make me happy. Cancer is not a fight and I am not losing. It has been a challenge, it has been a journey, but in no way am I losing. Cancer is a bully and it picked me, but I've done my best to stand up to it and not back down.

She finished the post with what seems to be a request on behalf of herself and her family, and signed the post from her entire family:

Please be gentle with us. I have made my decision, I know there are many cancer 'cures' out there and if you find anything that directly and positively works, I would love to hear it otherwise it will only cause us stress and the feeling we're not doing enough.

Sandra struggled both with her son and the medical system so she could provide him with care. Her son rebelled against the care that was provided, and Sandra did not feel as though the healthcare system welcomed her as openly as a caregiver as they would have had she been a parent of a younger child. As Sandra had been handling her son's Type I diabetes, she said: "*having helped managed his diabetic care and the zillion drugs and appointments that come with it, that part of the cancer diagnosis was less of a shock.*" Sandra shared with me the medical journal she kept during her son's journey

through cancer which included a detailed schedule of appointment and medication times, for both his cancer and his Type I diabetes. The medical journal is evidence of a mother who took her son's cancer diagnosis seriously and seemingly tried her best to provide the proper care to him, both as his mother and as his medical caregiver. Sandra said of her experience: *“parenting a child who is an adult is difficult enough as I struggle with letting go of control and he struggles to gain control.”* Laura stated that: *“every cancer patient needs somebody, it doesn't matter if you're an adult, a young adult, or a child, I think you need another adult there to kind of manage that medical side and keep the clear, rational head space.”*

Giving up control, even if it is partial, can be difficult for those who are used to being independent. The difference for EAs is that they are just beginning to experience their independence and become comfortable with it. To feel as though this independence is at risk could make them feel as though they need to keep control and try to be their own caregiver, which could cause increased stress in their parents. The mothers recognized through the experience that they did not have the control that they once had when their children were younger, and they were prone to trust their child's knowledge more. As a result, they had to give up control in some ways, but also take some on, which can be seen through the medical journal records, and attendance of medical appointments. By controlling some aspects, the mothers could have been able to deal with some of their fears, and also help their child navigate the cancer journey as having someone help to monitor and make decisions with you can make the patient experience easier.

Strengthening the relationship. All of the mothers recognized that their children enjoyed their independent lives and, that, even if they did not argue with their mothers

about relinquishing their independence, the mothers believed that their children still felt frustration. When discussing the frustrations her daughter experienced during the final months of her life, Melanie said to me

“Especially in the last two months where we felt like we, my husband and I, couldn’t go out unless we kind of had someone that we really trusted here with her and so she felt that frustration too, she was like ‘oh this is ridiculous’, like she couldn’t drive anymore and stuff like that.”

Sandra’s advice to parents who are facing a similar struggle is to treat their children as equals in their care, allowing them to make decisions and take responsibility for those decisions:

Listen to what they have to say and give options for them to decide, along with enough background information that the child can make an informed decision. Provide your point of view of course, along with your preference and reasons or rationale – but at the end of the day, recognize that the choice is up to your adult child. You need to learn to let go of some of the control over health management, as scary as that is. Your child will get the most benefit from care that he or she chooses and takes responsibility for.

Sandra summarized her experience very well:

By far, the most difficult part of what we went through was a struggle over providing care to a young adult who wanted independence. I think we are closer than ever to having a relationship where we are both respectful of our own space and cognizant of the different strengths we bring to our relationship.

All three of the mothers said that their relationships with their children grew stronger as a result of the experience, as evidenced by the following quotes:

“I would say that the experience has brought us closer together.” (Laura)

Being a medical caregiver and a mother and a father and friend all at once is difficult. Having a second disease thrown in, and then depression as well, was very difficult. However, our relationship has grown much stronger as a result. (Sandra)

Like I said, we had a really good relationship anyways, we got along well. I mean we had the usual mother/daughter things, but I think it strengthened that and made us appreciate each other even more and it was, and we had the time to appreciate our relationship as well 'cause she had those years and so I think it just strengthened it and made it deeper. (Melanie)

Despite having positive outcomes in their relationships with their children, the mothers struggled with effects to their personal health throughout the cancer journey, as described in the next theme.

Theme three: Walking on egg shells. Two of the three mothers experienced effects to their physical and mental health as a result of their EA child being diagnosed with cancer. It was difficult for the mothers to be sure of what to expect from one day to the next, as there is much uncertainty within the context of cancer. After her daughter suffered a blood clot which created further complications, Melanie took to her blog and wrote:

All these ups and downs and twists and turns have us all feeling like we're walking on egg shells. It's hard not knowing it's going to be okay even one half day to the next – changes can happen so fast. And even if a day goes well, you don't know what's around the corner and these days it seems like the surprise are not often good ones.

Days filled with stress. The overall experience of having a child diagnosed with cancer and going through treatment was difficult for all mothers. All three were overwhelmed and felt challenged at times. It was not surprising that the mothers experienced emotional reactions throughout the cancer experience. The mothers felt that they required a great deal of strength throughout their journey, specifically in order to avoid or lessen the amount of crying and/or grieving they experienced. Sandra said, “*I was quick to tears or upset constantly when not playing caregiver.*” Laura, whose

daughter had finished active treatment and was currently undergoing check-ins at the time of her interview, said, “*there are times when I still can’t talk about it without getting emotional.*” During her interview, Laura remained composed, although it was evident that her experience had greatly affected her, and that she cared for her daughter very much.

The mothers also experienced a great deal of stress, worry, and anxiety. Laura explained her experience as, “*you go into this sort of paralyzed mental state.*” Sandra said, “*my days were filled with stress and worry*” as she went through the experience. Stress significantly affected the mothers. For Sandra, the multiple roles and experiences she had throughout her journey heightened her stress and led to negative effects:

I worked from home and hospital in a very high level, executive, stress filled job, cared for him, emotionally as well as physically, maintained my new relationship, and also found out that I was pregnant shortly after my son started chemo. I ended up losing the baby later on and I attribute that in part to the great deal of stress I was under.

One of Sandra’s quotes was an incredibly poignant account of her experience, and shed light on the challenges she faced and how her and her son’s life was changed by cancer:

Overall, this whole experience has been extremely difficult. It resulted in my having to slow down my career, in me losing three pregnancies, but in making our overall family relationships much stronger. Additionally, I believe my son is now taking steps in recuperation that he perhaps has needed for a very long time – even before his diagnosis. We are all stronger people and I am just happy that we caught his cancer early.

Due to her history as a single mother for much of her son’s life, Sandra may have felt that her son’s cancer was just another responsibility that she needed to handle, and depended on her personal experience of resiliency to make it through this experience

During the time of diagnosis, Laura related her feelings as “*like you’re kind of falling deeper and deeper into the hole with each successive medical appointment.*”

Melanie felt much the same, but over a longer period of time as her daughter's cancer worsened and new tumours were found. After another disappointing day at the doctor's office, she wrote on her blog: "*naturally, we are once again horrified, disappointed, and very sad. We are feeling numb, tired, and a little hopeless.*" Reading through Melanie's blog, it seemed as though she was on a perpetual rollercoaster ride since her daughter had been diagnosed. Although there were times where she received positive news, and enjoyed vacations and experiences with her daughter and family, there seemed to be just as many times where the cancer worsened. It was evident how difficult her five-year journey was for her, given all of the ups and downs that she went through. All three of the women experienced long journeys with their EA children working through their cancer diagnoses and subsequent treatments. These journeys were full of uncertainty and deep emotional pain, with serious health consequences, in Sandra's case especially. Sandra seemed to be very isolated and highly stressed when compared to the two other mothers, and these differences appear to have contributed to serious health repercussions, as evidenced through her three miscarriages. Although each mother had a traumatic journey, the way in which the journey affected them seemed to be reliant on not only their relationship with their child, but also on their existing relationships, support networks, and coping skills.

Maintaining ourselves. Overall, the mothers took care of themselves physically. Exhaustion was, at times, all-encompassing, with long chemotherapy days. Laura said of the chemotherapy treatments "*after about three treatments, with nine to go, I thought we'd never get through it all.*" The mothers tried to take time to rest, but sometimes, there was no time. As a result of stress, Laura found that she began to lose her hair, which

eventually did grow back, and she developed high blood pressure. As mentioned earlier, Sandra had three miscarriages, which she attributed to stress. Miscarriages can not only affect mental health, but are also a very physical experience. Melanie did not mention any negative health effects, although her self-care was quite high from the beginning. When her daughter was diagnosed, Melanie looked at her husband and said: *“I’m not going to stop running and I’m not going to get fat because I don’t want to feel horrible about myself, I don’t want to add that on top of everything else.”* She continued to say, *“I think it helped a lot, because getting out and being active, like running or yoga, whatever, it helps you physically and mentally.”*

All three of the mothers engaged in some form of exercise, and noted that self-care was vital for them during their experience. Of her journey, Sandra explained: *“it feels like all I did was lay awake worrying about my work, my son, my pregnancy, my relationship...I never got enough sleep and it caused a spiral situation where I was always stressed and feeling burned out.”* She continued to say: *“exercise saved me – it gave me the only respite I had and kept my serotonin levels at least somewhat normal.”* At the beginning, Laura did not engage in self-care; she was ultimately motivated to join the gym and hire a personal when touring a gym facility for her son. Laura had struggled with the physical effects of stress, and commented that *“it’s definitely really important to look after yourself as a parent and physical exercise, whether you’re the parent or the patient, is good.”* Melanie explained her and her family’s outlook on self-care:

We just kind of try to be balanced. That was a very important thing to us because we know, you know how awful you feel if you don’t take care of yourself, and she was very much the same, she really tried to, self-care was important to her and we took the time, we tried to take the time we needed to rest.

Continuing, Melanie noted that how she described her and her family's life during the cancer experienced sounded ideal, but it was not always perfect:

I mean this sounds so ideal you know and of course there's all sides to it, you have days when you feel crappy and all of that kind of stuff too, but that was always kind of our goal is to try to maintain ourselves, spiritually, mentally, and physically as much as we could to put up with the bombs that kept dropping on us.

On her blog, Melanie wrote a post about her gratitude journal, epitomizing the struggle she faced between positivity and negativity:

I started off the year with a gratitude journal. I kept it up faithfully for a few years and it was great to help me focus on both the good and bad times but frankly last year every day it was becoming a huge chore and it was getting harder and harder to come up with things.

After reading a quote from Brother David Steindl-Rast, “*it is not joy that makes us grateful; it is gratitude that makes us joyful*”, Melanie was inspired to try writing in her gratitude journal again:

I realized that for now, during this hard time, many times that I feel grateful for have a flip side, for example: I'm so grateful that I can be home with her BUT I'm so ungrateful that she's going through this or I was so grateful for the great run I had on this beautiful morning BUT ungrateful that she can't run with me anymore. So I think I will change my journal to a 'Grateful not Grateful' journal – I think it's more real, more honest, more me.

Being positive takes strength. Sometimes, the strength was found in the determination not to be upset, as Melanie noted, “*the strength was just because we didn't want to spend all our days crying.*” It was difficult to see the positive in the situation, even after the imminent danger was gone, as evidenced by Laura, “*I don't know if it's...it's hard to say that it's positive. I mean, I guess it's positive.*” One way that Melanie mentioned she had been able to look past the negativity of the situation was “*just look for all the joy (all the love that is constantly being shown to us) and be grateful*

(we're together) and just do what needs to be done." It was easier to maintain a positive attitude, and keep strong, when the children were handling the experience well. Melanie's daughter *"handled it so well, it helped us handle it better I think too."* Melanie explained the struggle between maintaining a positive outlook and giving into the negativity, *"when we look for light at the end of the tunnel, sometimes all we can see is darkness."* Sandra did not mention any ways in which she attempted to stay positive throughout her experience. It seemed as though Sandra had a very negative experience when compared to Melanie and Laura, and, although she felt as though her relationships with her son and common-law partner were strengthened as a result, she had difficulty maintaining a positive outlook.

When her daughter died, Melanie seemed to struggle with coming to terms with how she may cope with her loss; grief was anticipated, but there was no clear idea of what was beyond that:

I'm sitting in my living room by myself and it is silent for the first time in days. In the freezer are the remains of copious amounts of food that has been prepared and delivered to our home by loving hands. On every spare surface are bunches of flowers – all sizes and shapes – all beautiful tributes in various stages of decay. In the corner sits a bag with cards and well wishes from so many and a book with names of those who came to pay their respects. There was a service that I think she would have loved and we were overwhelmed that so many wanted to share this with us. A walk to remember her favourite places. But there is something missing and my heart aches. And now it's all over, except for crying.

Although the mothers were able to maintain a level of self-care during their experience, they still encountered challenges in their work and social lives. The cancer journey seemed to alter the way in which these mothers viewed their world.

Theme four Your whole world is changed. A cancer diagnosis creates life changes not only for the patient, but also for the patient's immediate family, including his

or her parents. The mothers in this study faced changes in their work, social lives, and personal perspectives. In my interactions with cancer patients and survivors, it has been apparent that they view cancer as a life-changing experience. Indeed, many individuals, whether they be patients, family, or friends, appear to be changed by cancer. The identity of these mothers seemed to be the most affected, as they started to view themselves as mothers of children with cancer. These mothers' beliefs about what is important in life changed after the cancer diagnosis in their children. As a result, they have approached their lives in different ways since their journeys began.

We are no longer the same. Through listening and reading these mothers' accounts of their experience, it seemed as though the cancer journey had changed them. Their beliefs and thoughts of the world, including its impact on them, had been altered. It also seemed as though they started to describe themselves as mothers of cancer patients, which is not a characterization that they would have used prior to the cancer diagnosis.

Laura mentioned that she thought she would never have to experience her child being diagnosed with cancer, until it happened:

Well you always think these things aren't going to happen to you right, it was kind of out of the blue, her doctor said you know it's not like you did anything wrong, it's just you were unlucky you got this disease, so I guess it makes you more sensitive to people with that kind of situation and there are so many people that do go through life without ever encountering anything like this, or you think there are those people out there, and I think I was one of those people, but I'm not one of those people anymore.

For the mothers in this study, their idealized view of the world where they are protected from experienced such as a cancer diagnosis in their child, was shattered by their journey. A diagnosis of cancer removes the safety net of believing that you will never encounter such an illness; you no longer feel as though you are invincible. Melanie said, "we're just

always being those people, you know 'oh those are the ones with the daughter who had cancer.'” The way in which Melanie spoke of her experience suggests that being affected by cancer creates a shift in one’s identity, to the point that maybe people can never be who they were before the cancer.

The experiences that these mothers faced as a result of their EA children being diagnosed with cancer allowed them to live more mindfully, by living day to day. This can be explained as a reprioritization of what was, and is, important in their lives. Planning careers, vacations, and other important details of one’s life tended to fall by the wayside, as the mother struggled with caring for her ill child, and being the supportive yet not overbearing parent. Their self-identity seemed to change as they navigated their journey. Sandra explained, *“it [cancer] completely altered the life we [she and her common-law partner] imagined – my career and our life together.”* Melanie said, *“being at this stage [terminal] brings what you think and believe into focus in a way that never truly happens any other time.”* She went on to explain, *“your whole world is changed, what you thought was going to happen in your life is completely different.”* When asked if the experience changed her, Laura said *“I would say yes because I still, we’re not through the five years yet.”* Her statement resonates with the worry and fear of cancer recurrence that accompanies the five years of post-treatment check-ups her daughter now has to go through. When asked how the experience had changed her, Laura explained, *“well it makes me more, like I understand a lot more where people are coming from, even if they tell you that they have, that something’s happening that you might think ‘oh no, so what?’, but I have more sensitivity to it I guess.”* The mothers’ views of the world, and

their individual identities were also affected by the way in which their work and social lives experienced changes in response to their cancer journey.

Work and social life changes. Two of the three mothers had understanding employers which made it easier for them to take time off as needed and feel supported by their work environment, rather than having to worry about that aspect of their lives. Despite this, Laura's daughter's cancer diagnosis occurred during a very busy time at work, and she felt the strain of having to take sick and vacation days. At one point, she had used all of her sick and vacation days which resulted in a switch to part-time in order for her to continue to attend medical appointments with her daughter and be available as needed. Even though her workplace was understanding and allowed her to switch to part-time, Laura commented, "*I would have rather hung around at home and I couldn't really hang around at home, you know, I really had to go to work a lot of those days.*" Melanie also had an understanding employer, but still experienced vocational changes: "*just have to change our work arrangements, I mean I took a lot of time off work and my husband did too, and my son, and then I actually went on leave for the last few months of her life.*"

Sandra was employed in a high-level executive position and experienced difficulties with her employer. At the beginning, she was able to arrange to work from home full-time to care for her son, which also meant working from the hospital while her child received treatments. She explained:

I actually lost my job just before he was done chemo – I could definitely make the connection that it was because I was unavailable at the office as usual – although they said it was because the position was no longer needed, however they filled the same position six months later with someone else.

As a result, her career growth slowed, although she has since found employment which is not as stress-inducing. Laura made an important point about employment stress and issues when trying to be a caregiver:

You don't want to be dealing with the illness and money issues at the same time so I think I was okay without that support but it would have been nice to have been able to take the time off without having to take a 40% cut in income.

Two of the three mothers found that their social life, or the ability to spend time with those outside their family core, diminished when their child was diagnosed with cancer. For Sandra, *"I had no social life. There was no going out."* This could be attributed to her playing multiple roles and working in a high-level position, as well as caring for her son full-time. Laura had a group of mothers who she met with regularly prior to the cancer diagnosis, which continued after her daughter was diagnosed. This group subsequently became a source of support during the experience for Laura. Melanie was able to maintain much of her social life until her child's health began to ultimately decline, and the level of uncertainty which went hand-in-hand with terminal cancer made it difficult to make plans with others. She explained:

She had times when she was really good so we were still able to travel and we did things with our friends, and so it did affect it more in the last year and a half I would say where we couldn't, we really didn't quite know where she was at and she was going through chemo again and then we just never knew, she was in and out of the hospital a lot and that really started affecting our social life.

None of the mothers reported that friends pulled away from them or became distant when their child was diagnosed. Sandra, who noted that she did not have a social life during the experience, essentially said it was because she did not have time for it, rather than her friends avoiding her. Indeed, it was unclear whether Sandra had reliable and supportive friends even prior to her son being diagnosed with cancer. Throughout their journeys, the

mothers in this study experienced challenges to their lifestyles, sense of self, and level of functioning. An important aspect of being able to cope with these challenges was benefiting from positive support.

Theme 5: Being supportive of each other. The women experienced different levels and sources of support throughout their journeys. Laura and Melanie reported a great deal of support from family, friends, and their community. Sandra had very little support, and was hesitant to utilize her common-law partner for support as she had just moved in with him prior to her son's cancer diagnosis, and did not want to burden him. All three of the mothers noted that they wished there had been some type of formalized support, specifically a support group, which would have allowed them to discuss their experiences with similar individuals.

Laura and Melanie were able to readily access support from family and friends during their experience. Laura had very good support from friends, and had a specific group of mothers who would get together and talk about life in general, and they met more frequently as she dealt with her daughter's cancer. She described the group:

They're mothers of [year daughter was born] babies, mothers that I would have met taking her to school, so mothers of kids her age. So we would have got together a lot when the kids were younger and then a little less regularly but generally we were in touch most of the time.

She went on to say, *"I have this group of mothers, so I just email them all, so we meet regularly usually in a bar, but you know to get together and offer support, so they were great."* Given Laura's responses, I began to think that support from friends may differ for parents depending on how long they have lived in their geographical location. It was apparent that Laura had lived in her area since her daughter had begun school, at the very

least. This could have contributed to her strong friend base. Although Laura found that her family, specifically her brother and her sister-in-law were supportive should she need to talk, they were not geographically close, and so she depended more on her friends for support. Melanie found that family and friends were very supportive, noting: *“I mean a day wouldn’t go by we wouldn’t get like a card or a gift or something, like for five years, honestly, we had everything you could possibly imagine.”*

Melanie found that community support was strong during the five years her daughter struggled with cancer. She found that support was not only readily available from her family and friends, but also from strangers. There were fundraisers held, and support was readily given in terms of time, money, and gifts. She credited the kindness of strangers to her daughter, *“she was just so, the kind of personality that just attracted people so much.”* Regarding this experience, she noted, *“people are just trying their hardest to do something that will bring a smile to your face.”* Although she, at times, experienced difficulty accepting such outpourings of goodwill, she ultimately found that it was important to let others help her, because, by doing so, she was helping others. She was also actively involved in her church community, which she also mentioned as a source of support. Laura also found that neighbours and community members were willing to help and support her family when times were tough. In contrast, Sandra did not experience any community support during her journey.

Unfortunately, Sandra did not have family residing in the city where she lived and her social life was non-existent during her son’s cancer experience. She found that she was unable to speak to anyone except for her common-law partner. She described her experience:

It was extremely difficult to go through caring for my son and bearing all the stress and anxiety alone. It was a new relationship as well which added stress. Having said that the man I love is amazing and provided a lot of support as well. However, I was the one managing 90% of the journey as he's my son.

Sandra summed up her experience: *“I have to say it was one of the toughest times in my life without support.”* Although she had access to her common-law partner as a potential source of support, Sandra felt that she was ultimately alone in her experience, and that it would be unfair to request too much from her partner, as her son was not his and they only recently moved in together. There is the potential that, as a result of caring for a child with long-term health condition, and being a single parent for an unspecified amount of time with a high-level executive career, Sandra may have found it difficult to find the time to grow a close network of supportive friends. It was difficult not to empathize with Sandra while reading her transcripts and looking over the documents which she had provided to me. Although I empathized with each of the participants, it seemed that Sandra had indeed felt very alone during her journey, and her transcripts were some of the hardest to read.

Overall, the women found that their family and marital relationships became much stronger as a result of the cancer experience. These relationships in themselves can be sources of support as there are mutually beneficial interactions and less stress involved in maintaining the relationship. Two of the mothers, Laura and Melanie, had strong marital and family relationships prior to the diagnosis of cancer in their EA child, as well as community relationships, and found that the cancer only strengthened them. Melanie explained:

We had a good family life and we all enjoyed each other and being together and stuff so when this happened, we didn't have to repair relationships and I think that, we wanted to continue that just to be kind of able to be supportive of each other.

Melanie described how her and husband worked together during their journey:

There were times we were more distanced from each other, but I think in general we tried to remember kind of the core of what was going on and that we really like each other and wanted to be together and support each other.

Melanie's daughter's diagnosis did affect some aspects of her relationship with her husband, such as spending less time together as a couple: *"especially in the last two months where we felt like we, my husband and I, couldn't go out."* Melanie's daughter may have picked up on this tension, as dying, she made her parents promise that they would not get divorced:

It was funny because a couple of nights before she died, she'd say 'okay, you guys, you can't get a divorce' and we were like 'what are you talking about?' 'No when people's children die then they get a divorce 'cause they can't handle it' and we said 'no, we promise we won't get a divorce.' So that was one of the promises we had to make to her.

Even when the two partners in a marriage are working well together and have a strong bond, they each can have different perspectives, especially regarding important issues at hand. If they do not agree with one another, division in the relationship can occur, leading to strain. Laura said that although she and her husband generally communicated effectively throughout the cancer journey, she remembered specifically that there was tension in the relationship when they were not agreeing about their daughter's potential fertility treatment. Laura described it: *"well actually he was very anti-freezing the eggs and so we weren't really sure, I wasn't really sure where that was coming from, still not really sure where that was coming from."* Given that going through

with the fertility treatments would have delayed Laura's daughter's cancer treatments, it is possible that Laura's husband was against freezing the eggs because he did not want the cancer treatment to be delayed any further than necessary. It seems, however, that Laura and her husband never really discussed the issue together, as she still does not seem to understand his reasoning behind being against the fertility treatment.

For Sandra, her relationship with her common-law partner was at the beginning stages of cohabitation, and the cancer diagnosis placed stress on the relationship: "*it was a definite strain on our relationship having a young adult with a life threatening disease to care for – actually, with two diseases.*" As mentioned earlier, Sandra's life together with her partner suffered some adjustments, in that what they had imagined was not necessarily what was realistic after her son was diagnosed with cancer. This is in contrast to the two other women, who had been in their relationships for a much longer duration than Sandra, married and living with their children's birth fathers. This could have led to them being better positioned to manage relationship stressor. Despite the struggles Sandra and her partner faced, the relationship seems to have become stronger as a result of her son's cancer, and since her son's remission, perhaps because of the experience of overcoming difficulties together:

However, we are now married (as of [date] this year) and our family unit has grown stronger, with my husband and son having definitely bonded and my husband having grown very quickly as a parent (having never had a child).

Sandra summarized:

Overall this whole experience has been extremely difficult – it has resulted in my having to slow down my career, in me losing three pregnancies - but in making our overall family relationships much stronger" and "we are all stronger people and I am just happy that we caught his cancer early.

Although Laura and Melanie found support from their family and friends, all three of the mothers in this study reported that they lacked a way to connect with other parents going through similar situations. Many hospitals and clinics offer formalized psychosocial support for the patient and families affected by an illness, such as cancer. For Melanie and Laura, it was apparent that psychosocial support was made available to them at the hospitals should they have wished to take advantage of it; whether or not the support was offered by professionals well-versed in EA cancer was not clear. Sandra did not mention whether any professional psychosocial support was available, although it seemed as though, if it had been, she did not take advantage of it. The mothers have not have thought about the need for support until they had gone through the worst of the cancer experience and, on reflection, began to think that they could have benefitted from professional, knowledgeable help. In addition, during treatment, the mothers could have been narrowly focused on getting their child the proper medical treatment.

“So for professional help, I mean we did a little bit of counselling but there was some of that but other than that it was mostly just kind of the people around us.”
(Melanie)

“I mean they did offer us I think psychological help at the hospital if we wanted it but we never took advantage of it. So I guess in retrospect it might have been good to do that.” (Laura)

All three of the mothers wanted to have the opportunity to talk about their experiences with those who knew from personal experience what they were going through. They found that this type of support was lacking and essentially unavailable, and felt that it was something that the healthcare system could do better in the future for parents who are going through this journey.

Well it would have been really nice to have, sometimes I felt, even though there was so much around you, you feel alone because you're the only person you know who, well I would go 'okay, well should I go to a support group for parents of amputees or parents of you know young people with [type of cancer]?' but then trying to find those people were hard anyways and then to find both was also impossible. So that would have been nice to talk to people who were actually going through it. (Melanie)

"Certainly I think support for the patient, same age and the parents you know with kids the same age, is helpful." (Laura)

"Having someone with similar experience as a mentor would have been a benefit as we had no experience whatsoever in dealing with cancer in a young adult." (Sandra)

Summary

In summary, it appears that the mothers of EA children with cancer who took part in this study experienced many different psychosocial effects as a result of their experience. There is a lack of acknowledgement of the distinctiveness of the EA age group and, as a result, for the mothers of this group when cancer is involved. What is especially distinctive within emerging adulthood is the changing balance of control both due to the cancer and the age of the child. The participants' narratives suggest that, although for two of the three mothers support was often available from family, friends, and community, not everyone has that support. The mothers experienced changes to their physical and mental health, with examples including high blood pressure, hair loss, anxiety, stress, worry, and miscarriage. All three of the mothers experienced impacts in their employment. One mother lost her job during her son's cancer treatment, another mother had to switch to part-time, and the third mother had to take a leave of absence during the final few months of her daughter's life. The mothers' social lives were impacted, but having very strong connections beforehand can help to reduce the impact. Those with limited social lives beforehand, such as Sandra, can be very impacted.

The mothers' experiences suggest that emerging adulthood, as a developmental life phase, has specific challenges associated with it, particularly when cancer is present as well. Mothers struggled to achieve an appropriate level of caregiving, while still allowing their EA child to maintain their independence. As a result, conflict was experienced. The women also struggled with the lack of understanding and knowledge from the healthcare system about the specific needs of their EA child, and their own needs as a mother of an EA child with cancer.

Chapter 4: Discussion and Conclusions

The first research question was: “how does having an emerging adult child with cancer affect the parent psychosocially?” The results of this study suggest that issues specific to the EA child experiencing cancer included challenges with the healthcare system, not being heard, difficulty letting go, stress and navigating proper self-care, changes in identity and beliefs, and changes to work and social lives. Going through the cancer experience seemed to strengthen parent-child relationships overall, but still posed some challenges in regards to control and advice. Parents’ other relationships, such as social, familial, and marital, were both hindered and helped by the experience. Parents in this study reported negative mental health effects, such as stress and anxiety.

The second research question was: “what support is important to parents of emerging adults with cancer?” Support that was found to be available was offered by family, friends, and the community. Although briefly mentioned, psychological support was available for two of the three mothers, but was not used. Parents found that there was a gap in the support available to them, as they felt that they would have benefited from being able to speak with others who had similar experiences as them.

Interpretation of Findings

The results of this study can shed light on aspects of emerging adulthood, specifically how parents of EAs are affected by their child’s cancer, in part as a result of the parent-child relationship. The three parenting clusters that Nelson and colleagues described (2011) did not seem to describe the three mothers within this study. None of the mothers appeared to be uninvolved, controlling-indulgent, or authoritative. Laura could be seen as being partially controlling-indulgent, because she was low in

responsiveness in certain situations where her daughter did not want to listen, such as playing sports. Despite this, however, Laura had shared control with her daughter and, therefore, does not fully fit the criteria for this cluster. Melanie was much the same as Laura, as she had shared control with her daughter, and was not highly responsive in reacting to her daughter's life decisions. However, she was very involved in the medical processes surrounding her daughter's cancer treatment and ultimate death. Sandra could be described as authoritative, as she was high in responsiveness to her son's illness and his disinterest in relinquishing his independence. Authoritative parents also are low in control, however, and Sandra tried to exhibit high control at the beginning, although this slowly gave way to shared control with her son. Emerging adulthood has been described as a specific developmental life period characterized by identity exploration, instability, self-focus, feeling in-between, and possibilities (Arnett, 2004). Although they are legally adults at the age of 18, EAs tend to feel as though they have not reached adulthood until the age of 26 (Harms, 2003). Research has shown that executive functioning, including decision-making ability, continues to develop throughout adolescence and generally does not fully develop until age 25 (Blakemore & Choudhury, 2006). There are issues specific to emerging adulthood and cancer: (1) disagreement about what adulthood means for the parent versus the child, (2) differing perspectives, (3) medical decision making, (4) loss of newfound independence, and (5) parental control. As a result of these issues, and the different experience of having a child who is in an in-between state of child and adult, the expectations underlying this study were that parents would experience high stress and decreased psychosocial functioning. I also thought that the parent-child relationship would be altered by the experience, either positively or negatively. What I found was

that, although parents did experience high stress and some decrease in psychosocial functioning, it was not as pronounced as I had thought it would be. Despite this, however, all three of the mothers in this study believe that the effects of their experience, and the experience itself, were different as a result of the age of their child. These findings were present in theme one, which described how the mothers were distressed by their perception of the lack of understanding of their situation by the healthcare system. Parent-child relationships were altered by the experience. Although I originally expected that there would be more conflict in the parent-child relationships during the journey, it appeared that only one of the three mothers experienced a great deal of conflict with her child. All three parent-child relationships were positively affected as a result of the experience, with the parent-child bond strengthening. Theme two documented the disagreement about what adulthood meant and the differing perspectives between parent and child. Theme three captured how the mothers exhibited the effects of their experience through stress, worry, and physical changes, such as hair loss, and all three mothers combated these by participating in self-care. The mothers experienced varying degrees of identity alteration, changing from an individual, to the mother of a child with cancer. As a result of this, and their experiences, their beliefs and thoughts about the mortality of their child and themselves, as well as general beliefs about the outside world, were affected. These changes, including the effects on mothers' social and work lives, were documented in theme four. The final theme captured the support that was provided for the mothers, and the support that was perceived to be lacking.

Five themes were found in this study: (1) lost word; (2) he/she is an adult, but I'm having difficulty letting go; (3) walking on egg shells; (4) your whole world is changed;

(5) being supportive of each other. Themes one through four addressed the first research question, concerning the psychosocial portion of this study. Theme five addressed the second research question regarding support. Theme one represented the mothers' difficulty in contributing to considerations for their child's medical care within the healthcare system as they were parents of legally adult children. This in turn was related to how the difficulty mothers had letting go and accepting the adult status of their children in theme two. All three of the first themes contribute to mental and physical effects experienced by the three mothers. In addition, themes one and two highlight the liminal phase of emerging adulthood, as the difficulties faced with the healthcare system and learning how to let go, are very descriptive of the in-between feeling of this developmental stage. The changes that were experienced in theme four were demonstrated through the mental and physical effects reported by the mothers in theme three.

Research question #1: How does having an emerging adult child with cancer affect the parent psychosocially? The main research question for this study was how parents were affected psychosocially when their EA child was diagnosed with cancer. The results showed that the mothers involved in the study experienced psychosocial effects, such as increased stress, anxiety and worry, conflict within relationships, altered perceptions, and two of the three experience a decrease in or inability to maintain a social life.

Lost world. The mothers in this study found that they were not well heard by the healthcare system during their experience. They felt that if their EA child had been younger, and, therefore, treated in the pediatric unit, their experience would have been

different. They believed that their children, as well as themselves as an individual parent, would have been better cared for and understood. Since their child was an EA, parents felt that healthcare personnel would often not take into consideration the importance of their parental role during the cancer experience, reflecting the in-between world of EAs and their parents. Healthcare professionals have been found to experience uncertainty in regards to confidentiality and decision-making procedures in regards to carer involvement in the cancer setting, especially if the carer is a parent (Morris & Thomas, 2001).

Letting go. The ambiguity of the EA developmental stage is evident in the literature review. EAs are no longer children, yet they do not perceive themselves to be adults. As a result of this, EAs and their parents are in a liminal stage, as they experience a changing of roles and the transition process between leaving adolescence behind and achieving adulthood. Liminal space is a theory proposed by Victor Turner, who states that the liminal phase is “one of separation from a previous status or social state” (Cook-Sather, 2006, p.110). During this in-between phase, the transformative process occurs as individuals find themselves in an ambiguous state that is neither what they once were, nor what they are reaching for. As emerging adulthood is a developmental life phase that is neither adolescence nor adulthood, it could be said that the EAs and their parents are experiencing a liminal phase, whereby they ideally work together to achieve the EA’s independence. When cancer is part of the experience, it could potentially increase the confusion and distortion of roles during this transformative process, as issues around independence, medical decision-making, and control come to the forefront. EAs with cancer are in-between two spheres of care, and both they and their parents have to

struggle with the cancer diagnosis, as well as inappropriate place of care and its potential repercussions. An example that can be seen in the results of this study that speak to the liminal phase that these parents and children were in during their cancer experience, is the fertility decision for Laura's daughter. As an EA, Laura's daughter was the one who needed to make the choice of whether or not to freeze her eggs. Despite this, however, it seemed that Laura thought that it was important that she be involved in the decision. This may be because if her daughter did not undergo fertility treatments, there was the possibility that Laura would lose out on the opportunity to have grandchildren by her daughter. This can be a difficult idea to let go of, especially as these mothers were already dealing with the potential mortality of their children. Ultimately, Laura's husband disagreed with the fertility treatment as it would delay the cancer treatment, and she mentioned that she is still unsure as to why he was against it.

Research has shown that parents have difficulty relinquishing control of their children during the EA stage (Aquilino, 2006). In a study of parents of EA children, a third of the participants were found to experience reluctance in letting go of their EA children, saying that they were ill-at-ease with having less power to intervene, and they did not have enough information about what their EA children were doing with their lives (Kloep & Hendry, 2010). Similar to the findings from (Padilla-Walker et al., 2013), two of the three mothers exhibited shared control with their children, while one mother experienced her child holding on to personal control.

Through qualitative study, Grinyer (2009) found that many of the EA children in her study had to give up their independence and autonomy by returning home after being diagnosed with cancer, allowing their parents to care for them. The EA children for all

three mothers in this study lived away from home attending school full-time at their diagnosis; following this, the children moved back to live at home full-time and the mother resumed a caregiving role.

The decision-making capability of young people develops throughout adolescence and grows in emerging adulthood, switching the decision-making responsibility from the parent to the EA child (Leffert & Peterson, 1999). The mothers of daughters found that helping their daughters with the medical-decision making process came as a natural part of their parent-child relationship. This finding is consistent with Grinyer's (2004) finding that EAs will still request the advice and aid of others with decision-making processes during illness, and sometimes revert back to a state of dependence. The mother of the son found that he rebelled against her taking control, because she felt that he was not capable of making important medical decisions on his own. EA children, however, have the legal right to make their own medical decisions, and be the recipients of this information, choosing whether or not they want to share this with their parents (Grinyer). Healthcare professionals who are responsible for the EA's care may be uncertain about the procedure for sharing of information and decision-making (Grinyer). Other medical decisions, such as fertility preservation, can also be something of a concern for the EA population when they are diagnosed with cancer. Decisions such as these can add to the stress already being experienced. Sexuality and fertility tend not to be an everyday topic of conversation between parents and EA children (Brannen, Dodd, Oakley, & Storey, 1994) and, as a result, discussions about the EA child's fertility can be uncomfortable for many parents. Although not the case with Laura, parents tend to focus more on the treatment for and survival from the presenting cancer, rather than preservation of fertility (Quinn &

Vadaparampil, 2009). Many parents lack information on the topic of fertility preservation, and clinicians must educate both the parent and the EA child, while addressing both parties' concerns. This can be especially difficult if the parent and the EA child are at odds, and many clinicians are not equipped to handle these situations due to lack of knowledge and training for effective communication (Quinn & Vadaparampil). In a study of fertility information and communication for cancer patients 13 to 25 years of age, it was found that, although all but one patient received some information about the potential impact of cancer and treatment on his/her fertility, the majority of patients felt that they received incomplete or mixed information, resulting in confusion and uncertainty (Wright, Coad, Stark, & Cable, 2014). In this study, there was only one mother who acknowledged fertility concerns and frustrations with her daughter, citing confusing and mismatched information between the oncologist and the fertility specialist.

The results showed that there were differences between the struggles which the mothers faced with their children. Mothers with daughters mentioned that their relationships were strong prior to the diagnosis, and remained that way afterward, despite some minor conflicts. Lye (1996) found that mother-daughter relationships are generally the strongest of the four possible parent-child dyads (i.e. mother-daughter, mother-son, father-daughter, and father-son). Theorists have suggested that the socialization which daughters receive leads to a deeper appreciation and interest in creating emotional ties to family members, and is unlikely to change as they transition to adulthood (Chodorow, 1978; Lefkowitz & Fingerman, 2003). Daughters have reported that they feel supported when seeking to attain independence from their parents, yet they remain close to both of their parents as they transition from adolescence to emerging adulthood (Kenny &

Donaldson, 1992). When compared with sons, daughters report more contact and communication with their parents (Frank, Avery, & Laman, 1988). Sandra, the mother with the son, noted that she had difficulty with her son throughout his life prior to the diagnosis, and the cancer only increased this conflict as he fought for his independence and she fought for control. This struggle could also have contributed to the single-mother structure of their family. Although children raised in single-parent families have been shown to have greater maturity, sense of responsibility, and internal locus of control than children from two-parent families (Demo & Acock, 1988), single mothers are known to experience greater stress than married mothers (Kamerman & Kahn, 1988). Indeed, there is the possibility that the son felt a greater sense of responsibility to deal with his cancer on his own, yet his mother was not ready to allow him to embrace this, especially given that he also suffered from a second, non-related chronic illness. Furthermore, as mentioned in the results section, Sandra also stood out from the other two mothers as she was potentially an EA herself when gave birth to her son. Navigating the developmental stage of emerging adulthood while caring for a child, may have affected her parenting style, and thus the way she reacted when her son was diagnosed with cancer. Whether or not she herself was an EA (and only age ranges were collected), she was younger than the other two mothers when she was caring for her son with cancer, and may not have had as much time to build her coping and support resources, especially given her challenging career and son's pre-existing illness.

Days filled with stress. Having a child at any age diagnosed with cancer is overwhelming and can be detrimental to the parents' mental and physical health. This has been evidence through findings that parents of pediatric children with cancer have

experienced neglect of their own health care needs (Fletcher et al., 2010), weight gain (Smith et al., 2005), feelings of hopelessness and uncertainty (Bayat et al., 2008), decreased subjective health perception and life satisfaction (Fotiadou et al., 2008), stress and psychological distress (Dahlquist et al., 1996; Hoekstra-Weebers et al., 2011; Maurice-Stam et al., 2008; McCarthy et al., 2012), and have reported a significantly lower quality of life than population norms (Klassen et al., 2008).

Physical and mental health are inextricably linked. Mental illness or poor mental health can increase the incidence and prognosis of chronic health conditions and increase the likelihood of engaging in unhealthy lifestyle behaviours (Kolappa, Henderson, & Kishore, 2013). Two of the three women who participated in the study found that their physical health was affected, and all three women's mental health was affected as a result of the cancer experience. Increased stress, anxiety, and worry were reported for all three mothers, and this stress appeared to lead to physical effects such as high blood pressure and hair loss for one mother, and the loss of pregnancy for another mother. Heightened emotional reactions were common. The findings of this study regarding mental health were similar to what has been reported in parents of pediatric cancer patients, such as high stress levels (Dahlquist et al., 1996; Hoekstra-Weebers et al., 2011; McCarthy et al., 2012). The results for physical effects in the mothers were not similar to those of parents of pediatric cancer patients, as there was no indication of increased unhealthy lifestyle choices or weight gain (Klassen et al., 2008; Rosenberg et al., 2013; Smith et al., 2005).

In a study of mothers EAs with cancer, Grinyer (2006) found that mothers tended to neglect their own health needs. This study found that, although one mother had difficulty with self-care during the initial period of diagnosis, all three mothers overall

made an effort to maintain their self-care, or aspects of it, such as exercise, throughout their journey as they recognized the importance of remaining healthy. This study showed that the mothers who participated had a more nuanced trajectory of self-care than the mothers in Grinyer's study. Although neglect of self-care was present at the beginning for one of the three mothers, all three established a self-care routine that worked to alleviate the negative effects of their experience.

Impacts on work and social life. Employment and working conditions are a determinant of health, and having more control over the work environment, and fewer stress-related job demands, is associated with better health (Public Health Agency of Canada, 2013). Caregiving has been found to affect vocational ability, with impacts being felt through the parent leaving their job, missing time, experiencing decreased productivity while at work, or requiring a change at work to accommodate their caregiving role, such as switching to part-time (Lilly, Laporte, & Coyte, 2007). Indeed, parents of adolescents aged 13 to 17 with cystic fibrosis who reported a higher caregiver strain were more likely to require job accommodations, take time off, and experience decreased productivity (Neri, Lucidi, Catastini, & Colombo, 2016). Within this study, the three mothers found that their employment was affected as a result of their journey. One mother changed from full-time to part-time work, another took time off during the last few months of her daughter's life, and the third mother lost her job during her son's treatment and had to find new employment. Having to experience such drastic vocational changes increased the stress that these mothers were feeling, and caused some guilt and discomfort for one of the mothers who struggled between wanting to be home constantly for her daughter, yet trying to remain on top of her work load. These findings are similar

to the findings of a study on parents of pediatric cancer patients. Sloper (1996) found that, six months post-diagnosis, 50% of mothers and 37% of fathers had experienced negative effects on their employment, including resignation, being dismissed, reduced work hours and/or responsibilities, and increased stress and exhaustion, resulting from trying to catch up on missed work or leave requests being denied. Negative effects on employment can affect financial stability, also leading to increased stress. Sloper found that 18% of parents of children with cancer had reported a loss of earnings. I found that all three of the mothers had either experienced loss of employment, extended leave, or reduced hours. Sandra even lost her job during her journey, which resulted in loss of income. When work environments are compromised as a result of caregiving, whether it is a reduction of hours worked or loss of a job, there could be financial implications for parents. Income is a determinant of health, with higher income linked to better health outcomes (WHO, 2015b). None of the mothers in this study noted any financial difficulty as a result of the changes they experience in their work environments. This could be attributed to two of the mothers having financial security by way of their husbands, and the third mother potentially earning a high income prior to losing her job, as she held a high-level executive position. Financial instability, and therefore poorer health outcomes, could be a potential issue for other parents who do not have these advantages.

The ability to be social. When an individual experiences social stability, inclusion within cohesive communities, and good relationships, their health benefits (Public Health Agency of Canada, 2013). For two of the mothers involved in this study, their social life, and the ability to spend time with those outside their core family, diminished when their EA child was diagnosed with cancer. This result is similar to previous research reporting

that parents of pediatric cancer patients may limit social relationships as they begin to experience feelings of loneliness and isolation as a result of the caregiving burden (Bayat et al., 2008). One mother found that her social life remained intact for the most part, given that the group of mothers she spent time with were also a source of support for her, and had been a group that met regularly prior to the cancer diagnosis.

Sandra, as a single parent, allowed me to explore her different context. Although she lived with her common-law partner at the time of her son's diagnosis, Sandra specifically described herself as a single parent. Single parents of children with cancer have been found to experience cumulative stressors including financial strain, housing and geographic instability, and physical and mental health problems (Granek et al., 2014). When a parent has been providing physical care for the majority of their child's life, and/or has had sole physical custody, he or she may experience discomfort or resentment when a less-involved parent figure, such as a romantic partner, tries to get involved when their child is diagnosed with cancer (Kelly & Ganong, 2011). Stepparents have been found to step back from any decision-making when a child is diagnosed with cancer, although they are willing to offer opinions and support their partner and the child (Kelly & Ganong). Stepparents are also sometimes pushed away by their partners within this type of situation as their partners believe only they are able to make the decisions based on the biological relationship (Kelly & Ganong). Partners also tended to exclude stepparents to shield them from the blame if the situation were to have a negative outcome. Although Sandra noted that her partner was there for her and her son, and her partner developed a stronger relationship with her son as a result of the cancer experience, she ultimately felt that it was not his burden to carry.

It has been found that single mothers are generally resilient, with those in the mid-income range reporting higher resiliency than lower and higher incomes (Kjellstrand & Harper, 2012). Sandra, as a single parent, showed her resilience through maintaining her self-care despite her many setbacks, including loss of employment and multiple miscarriages. She has also shown her resilience through her unfaltering commitment to her relationship, culminating in a marriage, as well as her securing a new job. Overall, I found that the mothers within this study were resilient. This was suggested by their commitment to self-care, ability to strive for a new normal following the completion of the cancer treatment, and ability to discuss their experiences throughout this study. Although they encountered many difficulties during their child's cancer journey, and are still evidently processing their emotional and mental responses to the experience, it appeared as though the mothers did have positive psychological change (e.g. posttraumatic growth, PTG). Tedeschi and Calhoun (2004) sum up PTG:

Posttraumatic growth describes the experience of individuals whose development, at least in some areas, has surpassed what was present before the struggle with crises occurred. The individual has not only survived, but has experienced changes that are viewed as important, and that go beyond what was the previous status quo. Posttraumatic growth is not simply a return to baseline – it is an experience of improvement that for some persons is deeply profound.

This explanation is very representative of the women in this study; they not only survived their experience, but they also grew as individuals. They became aware of the mortality of themselves and their children, and have been able to empathize with others who may be going through similar situations. They appear to be more aware of the world around them, and are interested in making positive life changes.

Research question #2: What support is important to parents of emerging adults with cancer? Grinyer and Thomas (2001) found that parents of EA children with

cancer had the perception that they were less likely to receive adequate support from family and friends than they would had their child been younger when diagnosed. One of the mothers involved in Grinyer and Thomas' study found that, because her child was considered an adult and perceived as independent by others, practical help was not offered. Two of the mothers in the current study experienced a great deal of support from family, friends, and their communities. Support was available in the form of emotional support, provision of food and supplies, caregiving and respite care, and monetary donations, including fundraisers. The remaining mother, Sandra, felt that she did not have any supports readily available. She noted that there was no family or friends in the city in which she resided with her son and, although she was cohabitating with a partner, she did not feel it was his responsibility to care for her child. This study adds to Grinyer and Thomas' prior research by suggesting that the support which parents of EA children receive is not only based on the age of the child, but is also as a result of the family context. Each mother in this study had a different context, which affected the way she perceived her available support. How the family is structured, whether it be a two-parent or single parent, or with additional siblings, can affect the dynamic between the parent and child as they navigate the cancer journey.

Support systems enable mothers to take part in activities unrelated to cancer care (Fletcher et al., 2010). The preferred providers are non-professionals such as those individuals who share common experiences and reciprocate support (Finfgeld-Connett, 2005). The mothers involved in this study explained that they did not have a way to connect with other parents of EA children with cancer, and found that the other populations affected by cancer, such as parents of pediatric patients, had designated

support groups. Han and Belcher (2001) found that benefits from a computer-mediated online support group for parents of children with cancer included receiving information, sharing experiences, using writing as a means of communications, receiving general support, venting feelings, and gaining accessibility. Information giving and receiving was cited by 76% of the participants as the best benefit they gained from the online support group. Hospital-based open-ended support groups of parents of children with cancer have been found to offer parents a source of information on how to cope and maintain self-care (Foreman, Willis, & Goodenough, 2005). The overall perception of these groups by parents was that they were a place for psychosocial support and dialogue. Being able to speak to someone with similar experiences would have enabled the participants in the current study to have someone to ask questions of and vent their emotions with. All participants found that support was lacking both for themselves as parents of an EA child, as well as for their EA child due to a lack of acknowledgement of the distinctive needs of this age group and their family members.

The overall experience of having their EA child diagnosed with cancer was challenging for all of the mothers involved in this study. Mothers found that they were not understood during their journey, particularly by the healthcare system. They felt that their concerns were not being adequately heard and, at times, they were not recognized as their child's caregiver. Mothers reported that they had to find a balance between controlling and maintaining their child's independence, including how involved to be in the medical decision-making process. Days were filled with stress, leading to negative effects in physical and mental health for all the mothers involved in my study. Despite this, however, all three mothers were able to maintain a level of self-care throughout their

experience. The cancer journey called into question the mothers' beliefs and thoughts, including self-identity, and impacted their work and social lives. Support was found in family, friends, and the community for two of the mothers, while one mother reported that she felt her access to support was lacking. All three mothers noted the lack of appropriate peer-to-peer support, and said that they thought that parents in similar situations as them would benefit from this type of mutual support.

Relevance and Significance of Research

Very little research thus far has examined EA cancer, specifically the psychosocial effects and needs of parents of EA children with cancer. Although we are learning more about AYA cancer, few studies take a developmental approach and only Grinyer (2004; 2006; 2009; 2012) has studied parents of this age group (i.e. 18 to 25). As evidenced in the literature review, emerging adulthood is a specific developmental life phase that provides its own set of unique issues. This study has gone beyond what Grinyer found in her research by looking at the specific developmental life phase of emerging adulthood rather than the chronological period of young adulthood.

This study was also conducted using a qualitative case study methodology and revealed the many psychosocial issues that parents can face during their experience of their EA child having cancer. In addition, the current study also touches on the strengthening of the parent-child relationship as a result of the cancer experience, and enunciates the lack of formalized support for these parents. Grinyer (2004) used narratives to study how parents of EA children with cancer interacted with healthcare professionals. Grinyer found that there were both negative and positive interactions between parents and healthcare professionals, which I also found in my study. This study

added to Grinyer's research by highlighting the challenges mothers of EA children with cancer faced in regards to being understood and heard.

Given that the EA population and their parents are currently understudied in existing literature, it is hoped that interest will be generated for future research pertaining to EAs with cancer and their parents. In addition, this study adds to a greater understanding of how parents of EA children are affected when their child has cancer and in what ways they have been able to cope. It is also planned for the findings of this research to inform the implementation of support and health resources and programming for parents of EA children with cancer, as well as parents of EA children with other chronic, life-threatening illnesses. By understanding the challenges faced by parents of EA children who are diagnosed with cancer, meaningful support can be created for those who are involved in these situations.

Relevance to health promotion. The social determinants of health which were of particular interest in this study were primarily social support networks and access to health care, as well as physical environment (i.e. working conditions), gender, and self-care. Those who have greater support from family, friends, and communities have been shown to have better health (WHO, 2015e). With greater support, parents may potentially feel less stress and burden as a result of their EA child developing cancer, and, therefore, be better able to care for their child and initiate appropriate self-care. One of the major issues that was evident among all three women within this study was that there was a lack of support groups or opportunity to speak to other parents in similar situations. As the participants noted, there are support groups for parents of young children or caregivers in general, yet there is nothing for parents of EA children with cancer. Socially supportive

environments have the potential to reach many people and make a permanent change in the environment, making it highly advantageous when compared to individual-focused interventions (Kelly, Hoehner, Baker, Brennan Ramirez, & Brownson, 2006).

Health services are those that “include all services dealing with the diagnosis and treatment of disease, or the promotion, maintenance and restoration of health. They include personal and non-personal health services” (WHO, 2015e). Personal health services are delivered on an individual basis and are generally rehabilitative or therapeutic, whereas non-persona health services are those that are applied to large groups, such as health education, or non-human components of the environment (Adams et al., 2002). Appropriate health services for EA children and their parents, which take into consideration the unique issues relevant to cancer in emerging adulthood, are vital to good health. The results of this study can help inform the creation and enhancement of supportive health environments, which include access to health resources and opportunities for empowerment (Nutbeam, 1998). These supportive environments within the healthcare system would include proper care and acknowledgement of parents’ feelings at the hospital or clinic where the EA is being cared for, as well as informal or formal counseling and/or other support services where parents could connect with those in similar situations. For parents of children with cancer, caregiving strain has been found to be the most important determinant of health-related quality of life (Klassen et al., 2011). Psychosocial health services that address the strain that parents may be facing, and the liminal phase they could be in, should be made available to lower the risks of poor health-related quality of life, including poor long-term health outcomes. These environments could provide not only support, but also education on how parents can best

create and maintain self-care, including how to increase their resilience and protect themselves against negative mental and physical health effects. If these social support environments are created, parents will be more likely to have better mental and physical health and will, therefore, be better able to support their EA child through the experience. Healthcare services that are age-specific and take into account the discomfort EA children and, as a result, their parents, would feel if they were placed in a ward where most patients are older adults (i.e. over the age of 65), could increase good mental health and, in turn, promote physical health. Understanding that these parents have unique needs in this liminal phase as they balance between wanting to be involved in their child's care and allowing their child to maintain independence, is integral to providing population-appropriate support services.

A person's physical environment includes all aspects of their environment that contribute to good health, including the quality of air, water, housing, workplaces, and infrastructure (WHO, 2015e). For this study, employment and working conditions were the aspects of physical environment that held the most relevance. Those who are able to maintain a level of employment, particularly those who are also able to control aspects of their working conditions, experience better health (WHO, 2015d). In this study, I found that the mothers faced challenges to their work environments as a result of the experience of having their EA child diagnosed with cancer. For two of the mothers, a reduction in working hours was experienced, and the third mother lost her job. Although these mothers faced a loss in income, they did not mention that they struggled financially. For parents who do not have the advantages that these mothers had (e.g. partners who bring in income, and/or earning a high income prior to losing a job), financial insecurity could

be a challenge that they would face, which could affect their health. For parents of EA children with cancer, whether or not the parent had or has a supportive work environment, with job security, could have an effect on their health.

Regarding gender, parents may have different experiences based on whether their child is male or female and whether the parent is male or female. Research has shown that children are often unconsciously raised differently based on their gender, which affects the way they interact and engage in relationships with their parents. Daughters are often raised to cultivate and value emotional ties (Lefkowitz & Fingerman, 2003), which leads to them being closer to their parents than sons are (Kenny & Donaldson, 1992). Families who have EA daughters experience higher cohesion within their family than those with EA sons, and relationship cohesion is highest between mother-daughter pairings (Scabini & Galimberti, 1995). Although not as high in relationship cohesion than mother-daughter dyads, it was found that mother-son bonds are stronger than father-son bonds as EA sons disclose more to their mothers than to their fathers (Barnett, Marshall, & Pleck, 1992). The mother-son dyad within my study experienced a greater deal of conflict than the mother-daughter dyads, especially in the areas of medical decision-making and caregiving. Considering sons are generally raised to be more independent from their parents than daughters are (Proulx & Helms, 2008), it is not surprising that the mother in this dyad experienced rebellion from her son when she tried to take over as his primary caregiving following the cancer diagnosis. In addition to the child's gender, the parent's gender is also of importance. All of the parents involved in this study were female. When compared to fathers, mothers have been found to be the one to generally take on most of the caregiving responsibilities (Lee, 1998). In addition, women tend to

have more precarious, part-time employment compared to men (Lambert & McInturff, 2016).

Following a determinants of health approach, health promoters require evidence on which to base their programming, in order to appropriately address the concerns of the population of interest (Raphael, 2000). This approach is specifically relevant to the current study as the aim is to inform the implementation of programs which address social support networks, personal health practices and coping skills, and access to appropriate health services. Social support networks can increase self-efficacy and resiliency, leading to better health outcomes (Public Health Agency of Canada, 2011). In this study, I found that the two mothers who had access to support experienced less stress than the mother who did not have access to support.

Recommendations for health promotion professionals. Health promotion takes into account social and environmental interventions rather than focusing solely on individual behaviour. To be an effective health promoter, one must advocate for political, economical, social, cultural, environmental, behavioural, and biological factors favourable for good health. Health promotion works with not only the health sector, but other social and economic sectors, including the government, non-government, community organizations, industry, and the media, to coordinate action that will create the best opportunity for good health. To be a successful health promoter, one must take action by building healthy public policy, creating supportive environments, strengthening community action, developing personal skills, reorienting health services, and moving into the future (WHO, 1986).

My study suggests the importance of creating health services where the special needs of EAs and their parents can be met. From the findings of this study, it appears that cancer has a significant impact on these parents' psychosocial functioning, including overall health (i.e. mental, physical, and emotional), social and work lives, and life outlook.

Health promoters have the opportunity to address these gaps by advocating for the creation of socially supportive environments for parents of EA children with cancer. Addressing this gap may ensure that parents of EA children with cancer are well-supported through their experience, in order to eliminate or, at the very least, ease their psychosocial burden. Creating a supportive health environment such as formalized support groups, both in the hospital and/or community setting, as well as in an online format, is a way in which health promoters could initiate and advocate for a change in how this population is supported. Health promoters could create a handbook for these support groups which explains the specific psychosocial issues pertinent to this population, potential topics of conversation to increase health, and the ways in which to encourage participation in and promote the support groups to parents of EAs with cancer. To reach many parents fairly easily, it is recommended that health promoters collaborate with Cancer Chat Canada to create a population-specific online support group. Cancer Chat Canada (2015a) is a website that provides online support to people affected by cancer. Support groups are led by a professional psychosocial oncology counsellor and have 6 to 8 members, with weekly meetings for 10 to 12 weeks (Cancer Chat Canada, 2015b).

In addition, collaborating with Young Adult Cancer Canada to provide a series-based webinar specific to parents of EA children with cancer could be beneficial. This series would be provided by healthcare professionals, including health promoters, and could include topic-specific webinars, such as: (1) how to support your EA child, while maintaining your own health; (2) how to negotiate the healthcare system as a parent of an EA with cancer; (3) ways in which to initiate and maintain physical and mental self-care; (4) how to renegotiate living arrangements to minimize stress for both you and your EA child. It could also be beneficial to have a question-and-answer webinar with EA children who could speak to parents about their own experiences and share what worked and what did not work in their journey in regards to their parents' involvement. Providing a series such as this in a webinar format allows parents across Canada access, as well as provides the opportunity for parents to watch the video or listen to the audio recording after the webinar has aired.

Health education provides the motivation, skills, and confidence to take action for health improvement (Nutbeam, 1998). Although health promotion in itself is not enough to create permanent behavioural change, there is still merit in education being included in the overall health promotion framework. Creating educational materials on how best to support parents of EA children with cancer, designed for healthcare professionals, would be beneficial as these materials could be distributed Canada-wide. The handbook for creating in-person and online support groups could also be distributed Canada-wide and utilized in communities as needed. If there are parents who have experienced similar situations, they may be more likely to create a support group of their peers if they are provided with the proper educational material to do so. Creating health promotion

material such as self-care brochures for parents of EA children, or booklets with information on emerging adulthood, including its unique issues and how to best navigate the cancer experience during this developmental life phase, could be beneficial. Ensuring that materials include pictures of EA children with their parents in a way that makes it clear they are in a balanced caregiving-cared for relationship will help parents relate to the material. As mentioned by one participant in this study, current materials that are available do not indicate the EA population, and there is no information readily available for parents of EA children with cancer.

It is also important that healthcare professionals be made aware of the unique issues that may arise in this developmental life phase for both the parent and EA, such as how to best integrate the parent in the medical decision-making process while maintaining the confidentiality of the patient, providing age-appropriate accommodations where appropriate to eliminate discomfort for patient and parent, and providing clear information on fertility issues. Healthcare professionals also need to ensure they understand that parents may be experiencing their own psychosocial issues as a result of their experience, and so they need to attune themselves to these potential issues, and provide support and resources when appropriate. Providing training information sessions for healthcare personnel, or including training in post-secondary education, to ensure that healthcare workers understand what emerging adulthood is and how parents and their children may interact within the healthcare setting during a cancer diagnosis, is important. This type of training could help healthcare personnel to navigate the delicate balance between the patient's legal rights as an adult and the parent's need for knowledge and involvement. Morris and Thomas (2001) found that carers who were involved in the

medical events as they unfolded felt more enabled in their role than carers who were not welcomed into the medical setting. It was found that their involvement helped not only the carer, but also the patient and the carer-patient relationship. If the carer's position within the situation is legitimized, they are in more of a position to consider their own needs, and maintain their own health, alongside caring for the patient (Morris & Thomas). Changing the focus of cancer care from patient-only to carer-patient, or parent-patient, so that the needs of the dyad are addressed would be beneficial to the health of both parent and patient, as well as maintaining the relationship bond between the two individuals. It would also help those working in healthcare to understand that EAs may experience discomfort as a result of feeling in-between and out-of-place in the regular cancer wards, which could affect the stress, anxiety, and worry felt by parents. Additional challenges also exist when comparing rural and urban EA cancer patients. The three parent-child dyads within this study were all from large urban centres. It is important that healthcare practitioners and health promoters understand that EAs and their parents will not only face challenges as a result of their age, but could also potentially face difficulties because of their geographical location. Miedema, Easley, & Robinson (2012) utilized a subset of 30 EA participants from a larger qualitative study to represent a rural population from New Brunswick, and an urban population from the Greater Toronto Area. Compared to urban EAs, rural EAs often experienced delayed diagnoses and had to travel farther to receive proper treatment, as many did not have easy access to cancer treatment services within their town. As a result of this, there was an increase in out-of-pocket costs, which is difficult for EAs to handle on their own. This can lead to the requirement of EAs to be dependent upon their parents once again, at least for monetary purposes.

Advocating for change in caregiver legislation would also help to ensure job and income security for parents of EA children with cancer, which could in turn lessen negative psychosocial effects. It has been found that parents who have a lower household income experience higher caregiver strain (Klassen et al., 2011). Although necessary health services provided by physicians or received in hospitals are covered by a federal health insurance plan in Canada there are still out-of-pocket costs that parents can face when their EA child is diagnosed with cancer, such as cancer medication administered outside the hospital setting (Klassen et al.). For example, there are some oral and intravenous cancer drugs that are administered outside of a hospital which are not covered for cancer patients in the Atlantic Provinces and Ontario (CanCertainty, 2015). Parents have been found to continue to support their children financially during emerging adulthood, even if they are no longer residing with them (Sten Hartnett, Furstenberg, Birditt, & Fingerman, 2012). This assistance declines as the child ages, as a result of the parent perceiving that their child has less financial need and no longer needs to be dependent on them. It is likely that many parents would help out their children financially during a cancer situation, potentially infringing on their own economic stability. If the parent also resumes the caregiving role and must take time off work and, as a result, a cut in income, they could experience financial strain, which could increase caregiver strain and lead to detrimental health effects. Currently, the Government of Canada provides Compassionate Care Benefits through the Employment Insurance (EI) program for individuals who have to take time off work temporarily to be caregivers to family members who are gravely ill with a significant risk of death (Service Canada, 2015). These benefits can be provided for a maximum of six weeks, as long as the family

member who is ill has a significant risk of dying within 26 weeks. In addition, eligible caregivers can claim a caregiver tax credit on their tax returns if they lived with a dependent over the age of 18 who depended upon them as a result of impairment in physical or mental functions (Canada Revenue Agency, 2015). Under this program, parents of EA children could potentially receive caregiver tax credits if their child is living with them full-time during their illness as a result of impairment due to their cancer. Each province has its own caregiver legislation as well. In 2014, Ontario passed the Employment Standards Amendments act (Leaves to Help Families), which allows family caregiver leave, as well as critically ill child care leave (Ministry of Labour, 2014). The critically ill child care leave only applies to children under the age of 18, and so parents whose children are between the ages of 18 to 25 would not qualify. In addition, this Ontario legislation offers job protection that is unpaid and parents are, therefore, still taking a cut in income. In addition to the eight weeks of unpaid leave for caregivers of gravely ill family members, some provinces provide additional benefits to general caregivers. In Alberta, some employees who take on a caregiving role may be eligible for up to six weeks of Employment Insurance benefits (Government of Alberta, 2014). British Columbia's Employment Standards Act stipulates that employees can take up to five days of unpaid leave in each employment year to attend to the care or health of a child under the age of 18 in the employee's care, or to the care of health of an immediate family member (Ministry of Jobs, Tourism and Skills Training, 2015). New Brunswick, Newfoundland, and Prince Edward Island follow similar models. New Brunswick grants employees up to three days off per calendar year for family responsibility (Government of New Brunswick, 2014), Newfoundland provides seven days (Labour Relations

Agency, 2015), and Prince Edward Island gives three days (Department of Justice and Public Safety, 2010). Quebec is the only province that offers up to 12 weeks of unpaid leave, four weeks above the federally sanctioned eight weeks, to employees who are required to help with the care of an immediate family member as a result of an accident or serious illness (Commission des Normes du Travail, 2015). Employees can request an extension of up to 104 weeks, but only if the child is a minor and suffering from a potentially fatal serious illness. Quebec also offers employees ten unpaid days off per year to fulfil obligations related to the care or health of their children under the age of 18. In Nova Scotia, caregivers of low income adults aged 19 and older who have a high level of disability or impairment, determined by a Home Care assessment, can qualify to receive \$400 per month (Government of Nova Scotia, 2015a). To be eligible, the caregiver must provide 20 hours or more per week in assistance. Both Nova Scotia and Saskatchewan offer Critically Ill Child Care Leave, but the child must be under the age of 18 for the parent to qualify (Government of Nova Scotia, 2015b; Government of Saskatchewan, 2014). Healthcare is a provincial responsibility, and health promoters need to advocate for better caregiver legislation within the provinces so that parents of EA children can feel better supported if they need to resume the caregiving role. Policy changes are needed to allow parents of children over the age of 18 who are unmarried to be able to have time off of work, while maintaining job security. Parents of EA children should also be able to apply for a caregiver stipend to offset loss of income during time off work, such as the caregiver stipend available to eligible adult caregivers in Nova Scotia (Government of Nova Scotia, 2015a).

Study Limitations and Benefits

It is not uncommon in qualitative studies for the methods to undergo some changes based on the study. The methods did change somewhat in this study as data was originally to be gathered through an asynchronous online focus group, and was changed to a case study approach, as a result of low recruitment. Participants who originally signed up to respond only to an online discussion forum may have been either more or less open than they were when conversing directly with me, as they had been expecting to talk back and forth with other participants. Furthermore, the case study approach requires additional documentation, which was a little harder to gather from participants who had originally signed up to be solely in a discussion group. It proved difficult to push the participants for further documentation beyond what they openly offered, given the delicate nature of the topic.

Participation in this study many not have been easily accessible to parents in rural communities, as much of the recruitment was done through online advertisements across Canada. Although rural communities do have access to the Internet, service tends to be slower and there are often data caps enforced (Dobby, 2015; Eastlink, 2016; O'Rourke, 2013). Interviews were also conducted mostly by phone and email, which not have been accessible to some parents and could have affected participation. Although the three participants in this study represent different provinces across Canada, they are all from cities and, therefore, do not represent rural parents who may have different experiences as a result of their rural setting. The aim of this study was to understand how parents of EA children with cancer were psychosocially affected. Unfortunately, despite my best efforts, there were no fathers recruited for this study. This means that the findings are more

relevant to mothers' experiences as compared to fathers. There was also a lack of ethnic diversity in the participants, as all the participants identified as Caucasian. As this study involved sensitive subject matter, it is possible that potential participants would not have been interested in participating as they did not want to discuss their experiences with a stranger, and/or may be unable to talk about the experience without becoming overly emotional.

The participants' responses may have been affected by the age and/or gender of the researcher. Although participants may not have experienced discomfort regarding gender, as all three participants and the researcher were female, age could have affected responses, as I, the researcher, was an EA during data collection. The participants may have been more comfortable expressing themselves and explaining their journeys had I been an older adult, or someone who may have had children.

Data was not requested from other family members, as the participants were made aware that their spouses were welcome to participate in the study and share their own experiences. In addition, there were some gaps in the data that was collected from the participants. For example, it would have potentially been beneficial to have more pictures and other types of data sources from the participants. Given the delicate nature of the topic at hand, however, I decided as the researcher not to press the participants to share sources with me that they may not have been ready to share. I gave examples of data sources for them in their informed consent, and gave some prompts.

Case studies tend to be discouraged as a research strategy by many as they are seen to be lacking in rigor, are ungeneralizable, demanding of time, as well as creating a large number of records, that can be viewed as difficult to read (Yin, 2013). These issues can be linked to researchers either not understanding what a case study really is when they use the methodology, or not going in depth enough. The case study, when used properly, can offer in depth knowledge about specific individuals, groups, organizations, or social and/or political phenomena (Yin, 2013). The use of case study methodology offers research flexibility which is not often found in other qualitative approaches, as they are designed to suit the case and research question (Hyett, Kenny, & Dickson-Swift, 2014).

Although this study had three participants, it has been found that qualitative studies require fewer participants than quantitative studies to achieve rigor. As case studies are particularly focused on gathering rich data through various mediums, Morse (2000) suggests that fewer participants are needed. Experts say that it depends on the population and topic being studied, and a researcher can achieve rigor with as little as one case (Baker & Edwards, 2012). If a researcher is studying a hard to access population, such as the population in this study, then reaching only a few people can provide valuable insight and understanding (Baker & Edwards, 2012). I faced difficulties when recruiting participants for this study. As cancer is relatively rare during the EA life phase, the population of parents of EA children with cancer is generally smaller than parents of other age groups. In addition, the topic of this study was an emotional one, which could have deterred some parents from participating. Two of the mothers were over one-year post-treatment of their child, while one of the mothers joined the study only a few months

after her daughter died of cancer. I found that, in corresponding with potential participants, some parents who originally thought they would be able to participate, decided that the study would bring up too many emotions for them and declined to participate prior to the informed consent phase.

Suggestions for Future Research

Considering the limited research in the area of EA cancer, and the lack of research concerning parents of EA children with cancer, this study can act as a starting point for future research within this area. The lack of research in EA cancer, as evidenced by the literature review, highlights of the need of research to be conducted in this area; this study's findings suggested ideas for future research.

First, it is evident that more research needs to focus on the EAs themselves. Researchers who specifically take into account the developmental life phase of emerging adulthood in relation to cancer have generally looked at EA survivors of childhood cancer (Balling, 2003; Gerhardt et al., 2007; Gerhardt, Vannatta, Valerius, Correll, & Boll, 2007; Thompson, Long, & Marsland, 2013; Thompson, Marsland, Marshal, & Tersak, 2009). A study conducted in 2012 by Patterson, Millar, Desille, and McDonald, examined the unmet needs of EAs with a cancer diagnosis. This study was located in Australia and found that EAs presented with a range of needs, including information needs (e.g. fertility, care/treatment, psychosocial services), healthcare-related needs (e.g. style of communication, privacy and consent issues, concerns associated with hospital facilities), daily living needs (e.g. educational, occupational, and practical support), interpersonal support needs, identity renegotiation needs (e.g. autonomy, transition, and existential issues), and help dealing with emotional distress. In study EAs themselves,

researchers can include how these children relate to their parents during the cancer experience, as well as how they might navigate and experience other areas of their life, such as their sexuality, fertility, body image, and interpersonal relationships.

Second, focusing on the gaps in support that parents in this study voiced would be beneficial. For instance, a study could be conducted which follows participants of a CancerChat Canada support group designated for parents of EA children with cancer to understand how these parents benefit from this type of support, and whether this is an appropriate medium for support. Another potential case study could examine both parents of the EA, to understand the changes, both positive and negative, to the relationship dynamic, including communication, intimacy, and support. It would also be beneficial to study parents of EA children who are situated in rural communities, and may experience additional barriers to healthcare services that the participants in this study did not face, as they live in large cities.

In addition, resilience in parents of EA children could be an area to be explored, as this may allow for a deeper understanding of how chronic illnesses in EA children affect parents. Resilience-specific studies could also explore how resilience could influence the parent's ability to cope and navigate the cancer experience along their EA child. In general, innovative strategies that target male participation in research studies would not only benefit this area of research, but research studies in general. Research that specifically targets fathers of EA children with cancer would also be informative to the overall literature on EA cancer, as fathers may have very different experiences than mothers. Research regarding the ease of recruiting fathers for participation in studies is contradicting. An early review showed that adult men are less likely to participate in

research than adult women (Rosenthal & Rosenow, 1975). Despite this, it was found in a study of fathers' participation in child psychopathology research that the preconceptions of low father participation that researchers hold may lead to researchers being less likely to approach and/or recruit fathers, or have selection bias (Cassano, Adrian, Veits, & Zeman, 2006). Within my study, only one father responded to an online recruitment advertisement, and he was not successfully recruited as he did not respond to my attempts to have him complete the informed consent. As this study had only Caucasian participants, looking at the experiences of parents with different ethnicities is also important, as it may provide insight into how parents may be affected based on their culture. There is evidence that research is lacking in the area of health of Canadian visible minorities. In a review of 99 studies published between 19878 and 2014, Kan, Kobayashi, Lee, and Vang (2015) found that only five studies compared visible minorities with Caucasians on specific health conditions and/or behaviour when examining nationally representative data. In addition, many studies did not distinguish between immigrants and Canadian-born visible minorities. Purposeful recruitment strategies would be needed to increase participation in studies of visible minorities in Canada. There are likely to be differences in how parents and EA children experience the cancer journey both separately and together as a result of their cultural background. For example, EAs in China are believed to be affected by the historical, socioecological, and cultural conditions of China (Nelson et al., 2013). Differences could exist between countries, and also within countries as different ethnicities and cultures combine and bring with them their historical backgrounds and traditions.

Conclusion

The purpose of this study was to understand how parents are affected psychosocially when their EA child is diagnosed with cancer. Although there is research by Grinyer (2004; 2006; 2009; 2012) on the experience of parents aged 18 to 25 with cancer, she does not specifically look at how the developmental life phase affects the situation, and rather utilizes the age period as a chronological marker. As a result, there is no research that looks at parents of EA children with cancer, and this study has helped to fill a gap in the literature. A cancer diagnosis poses the risk of having a significant impact on not only the EA, but also his/her parents.

The findings demonstrate that it was challenging to be a parent of an EA child diagnosed with cancer. Parents were faced with a struggle between allowing their child to maintain their independence while trying to control the situation they were faced with. Changes in work and social life, physical and mental health, and life beliefs and outlooks, were experienced. A strengthening of relationships, both parent-child and within the family as a whole, was found for all three participants.

Emerging adulthood creates specific challenges for potential parent-child conflict. As Tanner (2005) explains: "Parent-child conflict during adolescence most often revolved around the concrete tasks and rules of daily functioning, the conflicts of emerging adulthood revolve more around the psychological component of establishing self as a separate, yet connected individual" (p. 29). Grinyer (2009) found that conflict increased in parent-child relationships, around contrasting ideas of independence when EAs were diagnosed with cancer. Given these findings, it was possible that parents of EA children with cancer would experience conflict as a result of not only the developmental

life phase of their child, but also as a result of the cancer diagnosis and the journey itself. The findings of this study found that there was more of a struggle for the mother with the son who was diagnosed, as opposed to the mothers with daughters. The woman with the son found that they both struggled to gain control in a situation where he was very ill and required care, but did not want to relinquish his independence.

Similar to parents of pediatric cancer patients, participants experienced changes in physical and mental health. These changes included high blood pressure, hair loss, anxiety, and worry. Regarding work, all three of the participants had to alter their work conditions, with one switching to part-time, one taking a leave of absence, and one being dismissed. All of the changes that were experienced were attributed by the mothers to high levels of stress, and the demand of caring for an EA with cancer. All three of the women's children returned home to live full-time when they were diagnosed with cancer, and the women resumed full-time caregiver roles.

An important issue for parents of EA children with cancer that is apparent from this study is the lack of support available to them. All three mothers would have appreciated the opportunity to be a part of a support group or talk to another parent that had experienced a similar situation, as they believed that they would have benefited from peer-to-peer support. The provision of this type of support is important, and could be viewed as vital for those parents who are not able to access support from family and friends.

Health promotion professionals are well-positioned to advocate for change in policy and create interventions for supportive health environments that will better support parents of EA children with cancer and other chronic illnesses. Creating supportive health

environments that take into account social support networks, employment and working conditions, policies around caregiver legislation, education for healthcare professionals on the unique needs of this population, and education designed for this population around self-care and maintaining good psychosocial functioning, will enable parents of EA children with cancer to lead healthier lives during a trying time, and potentially alleviate negative health outcomes.

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Appendix A: Kijiji and Reddit Advertisement

Subject Line: Wanted: Research participants to talk about the experience of being a parent of a young adult with cancer

Message:

Seeking participants for a study of the challenges of being a parent of a young adult who has cancer.

Does this describe you?

- Current resident of Canada
- English speaking
- Have a child who has been/was diagnosed with cancer between the ages of 18 to 25 (must be the first diagnosis of cancer)

If this describes you, you may be interested in taking part in our study. We are looking for people to take part in an interview where you will answer some questions from the researcher about your experience and post responses to other participants in similar situations. You will also be asked to submit any documentation (for example, photographs, records, and/or journal or diary entries), that you think may be useful to the study.

Eligible participants will have a chance to have a cancer-related organization of their choice entered into a draw for a donation of \$100 which will be made on behalf of the study.

If you are interested in participating or would like to receive more information, you can contact Lisa Fisher (lead researcher) by email at cancer@dal.ca

This study has been approved by the Dalhousie Health Sciences Research Ethics Board.

This research is being conducted by:

*Lisa Fisher, Principal Investigator
Master of Arts Health Promotion Candidate
Dalhousie University*

Appendix B:Poster #1

Was Your Child (18-25) Diagnosed with Cancer?

Seeking participants for a study of the
challenges of being a parent of a young adult
who has cancer

You would:

- Take part in an interview with the researcher and supply any documentation you feel comfortable sharing
- Be able to enter a cancer-related organization into a draw for a \$100 donation

To take part, you:

- Are a current resident of Canada
- Are able to speak English
- Are a parent of a child who has been/was diagnosed with cancer between the ages of 18-25

For more information, contact Lisa Fisher at cancer@dal.ca



“Cancer in Emerging Adults: Parents’ Psychosocial Challenges”

cancer@dal.ca

Lisa Fisher, Lead Researcher
MA Health Promotion Candidate

Was Your Child (18-25) Diagnosed with Cancer?

Seeking participants for a study of the challenges of being a parent of a young adult who has cancer.

You would:

- Take part in an interview with the researcher and supply any documentation you feel comfortable sharing
- Be able to enter a cancer-related organization into a draw for a \$100 donation

To take part, you:

- Are a current resident of Canada
- Are able to speak English
- Are a parent of a child who has been/was diagnosed with cancer between the ages of 18 to 25

For more information, contact Lisa Fisher, Lead Researcher, at cancer@dal.ca



"Cancer in Emerging Adults: Parents' Psychosocial Challenges"

This study was approved by the Dalhousie Research Ethics Board

Appendix D: CancerFightClub Blog

When someone is sick, or diagnosed with a chronic illness, the focus tends to be on the individual facing the diagnosis, rather than on those who surround them and support them. I have been fortunate to not have family members diagnosed with cancer, and have only known a few family friends who have navigated that road. Through my interactions with them, I began to understand that relationships were often altered when faced with a diagnosis, and the support system that the cancer patient utilized was not supported themselves. Through my current position with Breast Cancer Action Nova Scotia, I see our organization being under-utilized by support persons as they view us as existing for only the patient, when in reality, we exist for anyone who is affected by breast cancer.

I graduated from a psychology honours undergraduate degree in May 2012 and I have an incredible passion for mental health, psychosocial influences, and relationship interactions. In 2013 I chose to enrol in the Master of Arts program in Health Promotion at Dalhousie University, because I wanted to engage in primary prevention, rather than tertiary. In short, I wanted to reduce the risks and prevent the problems from happening, instead of trying to fix something that was already broken.

My previous research in my undergraduate career focused on emerging adults, which are those adults between the ages of 18 to 25 who are distinguishable from AYA by socio-emotional, specifically five main features: identity exploration, instability, self-focus, feeling in-between and possibilities. While reviewing the literature I came to realize that there is very little research on emerging adult cancer, and no research that looks at parents of emerging adult children with cancer. Most of the research examines parents of pediatric cancer patients, with some research on parents of adolescents. Given the lack of research in this area, I decided to focus on parents of emerging adult children with cancer and explore a topic of interest to me: psychosocial challenges.

Psychosocial can be described as anything that relates to psychological development, when taken in context of one's social environment. For my current study, I am looking at how parents are affected mentally, socially, and emotionally by the experience of having their emerging adult child diagnosed with cancer. I want to know what parents are dealing with and how they believe they could be best supported in order for the health care system, organizations, and society to create health promoting initiatives and supports specifically for this population.

I am currently in the recruitment stage of my research and am looking for parents of emerging adult cancer patients who are interested in participating in an online discussion forum. Parents will answer some questions about your experience which I've posted and then post responses and engage in conversations with other parents in similar situations. Eligible participants must be a (1) current resident of Canada; (2) English speaking; (3) and have a child who has been/was diagnosed with cancer between the ages of 18 to 25 (must be the first diagnosis of cancer). If you would like more information, please feel free to contact me at cancer@dal.ca.

Appendix E: Interview Guide

Hello. I want to thank you for choosing to participate in my research study titled “Emerging Adult Cancer: Parents’ Psychosocial Challenges”. My name is Lisa Fisher and I am the lead researcher on this study. You will be asked a series of questions about yourself, your child, and your experience. Your responses to these questions will be recorded and used for the purpose of this study. If you are uncomfortable answering any question at any time, please indicate that you do not wish to answer the question.

The first set of questions are demographic questions which will ask information about you and your child.

Demographic Questions

Participant Information

1. What is your age
2. Are you male or female?
3. What is your ethnicity?
4. Are you single, or married/common law?
5. What is your relationship to the child (e.g. mother, father, step-mother, step-father, other)

Information about your child

1. Is your child male or female?
2. What was your child’s living situation when diagnosed?
 - a. Lived at home full-time
 - b. Lived away from home for the majority of the year (e.g. for university) but returned home at times (e.g. for the summer and holidays)
 - c. Lived away from home full-time
3. What was your child’s living situation after diagnosis?
 - a. No change in living situation
 - b. Returned to live at home full-time or part-time
 - c. Left home to live away full-time or part-time
4. If your child did move out of your home, at what age did he or she move out?
5. What was the age of your child when he or she was diagnosed?
6. How long has it been since diagnosis (please indicate time in years and months)?
7. What type of cancer was your child diagnosed with?
8. What stage of cancer was your child diagnosed with?
9. Has treatment (active and/or palliative) ended?
10. If treatment has ended, how long has it been since it ended?

I am now going to ask you a series of questions about your personal challenges.

1. How might your experience of your son or daughter's cancer have been different if he or she had been a young child, a teenager, or an adult (aged 30 or older)?
 - Prompt → Have you considered issues such as independence versus dependence of your child, medical decision making, different perspectives between yourself and your child regarding his or her cancer care and his or her abilities as an adult, and parental control?
2. Do you believe that the experience of your son or daughter's cancer has affected you personally and, if so, in what ways?
 - Prompt → Have you considered both the positive and negative effects that this experience may have caused?

I will now ask you some questions about your relationships.

1. Has your relationship with your son/daughter been affected by this experience and, if so, how?
 - Prompt → Your relationship may have become better, worse, or may have remained the same. Have you considered the ways in which your relationship with your son/daughter may have changed (for example, levels of communication, enjoyment, pride, etc.)?
2. Has your social and/or work life been affected by this experience and, if so, how?
 - Prompt → Have you considered things such as quality, frequency of attendance, and/or inclusion/exclusion in activities?
3. Have you experienced any changes in your marital and/or intimate relationships since your son/daughter was diagnosed and, if so, can you describe these changes?
 - Prompt → Have you considered aspects such as sexual desire, fulfilment and engagement, and intimate communication?

I will now ask you questions about support.

1. What supports, if any, have you received during this experience?
 - Prompt → What types of support have you received (e.g. emotional, financial, help with household tasks, etc.)
2. What support do you think would have helped you during this experience?
 - Prompt → Why do you believe that these supports were not readily available to you? Why do you believe that you would have benefited?
3. What advice would you give to parents going through a similar situation?

That concludes the interview portion of the study. I want to thank you for taking the time to participate. Would you like to enter into the compensation draw?

If yes → Please tell me the name of a cancer-related organization or cancer hospital ward that you would like entered into a draw for a \$100 donation made on behalf of the study.

Appendix F: Informed Consent



Project Title: Cancer in Emerging Adults: Parents' Psychosocial Challenges

Lead researcher:

Lisa Fisher

MA Health Promotion Candidate

Lisa.Fisher@dal.ca

Supervisor

Dr. Lynne Robinson

Dalhousie University

Lynne.Robinson@dal.ca

Introduction:

We invite you to take part in a research study being conducted by Lisa Fisher, who is a student in the Master of Arts Health Promotion program at Dalhousie University. Taking part in the research study is up to you; it is entirely your choice. Even if you do take part, you may leave the study at any time for any reason. The information below tells you about what is involved in the research study, what you will be asked to do, and about any benefit, risk, inconvenience, or discomfort that you may experience.

Please ask as many questions as you like. If you have any questions later, please contact Lisa Fisher.

Purpose and outline of the research study:

This research study looks at how parents of emerging adult children (those who are between the ages of 18 to 25) with cancer might be challenged by the cancer diagnosis. As most of the current research around children with cancer is based on studies with young children and teenagers, we are hoping to gain insight into the effects on parents of children with cancer in this age group (18-25).

This study includes some questions about personal information (for example, your age and sex), as well as some questions about your child (for example, the age at which he or she was diagnosed and the type of cancer which he or she was diagnosed with). This study also includes participation in an interview (email, phone, or Skype), and sharing documentation of your experience with the researcher.

Who can take part in the research study?

You may take part in this study if you are the parent of a child with cancer who is/was between the ages of 18 to 25 when diagnosed. This must be your child's first cancer diagnosis. You must be living in Canada and have a good understanding of the English language.

How many participants are taking part in the study?

Due to the nature of the study, we are unable to specify the exact number of participants. Despite this, we are estimating that between 2 to 4 people will take part.

What you will be asked to do:

To help us understand how parents are affected when their child (aged 18-25) has cancer, we will ask that you participate in an interview with the lead researcher. This interview can be done via email, phone, or Skype. You will be asked demographic questions which include personal questions (for example, your age and sex), as well as questions about your child (for example, the age at which your child was diagnosed and the type of cancer your child was diagnosed with). You will then be asked questions by the researcher about the research topic. If you are uncomfortable answering a question that the researcher has asked, you can say that you prefer not to answer. There are no right or wrong answers. The entire interview will take approximately 30 minutes to 45 minutes, although this can take shorter or longer, depending on what you wish to contribute.

You will also be asked to share documentation of the experience you have had. This documentation includes diary/journal entries, photographs, and any other materials you believe could be beneficial to this study. These materials can be scanned and emailed to the researcher, or can be mailed to the researcher using the address provided in the email scheduling your interview time.

Possible benefits, risks and discomforts:

Potential benefits that you may experience by taking part in this study are finding comfort and support by discussing your experience with the researcher. Although participating in this study might not benefit you, we might learn information that will benefit others.

Risks with this study include the potential to experience emotional or psychological distress and/or discomfort, given the sensitive nature of this topic. The lead researcher will be providing a list of support groups and organizations, as well as helpful coping methods to all participants by email when the interview is scheduled. The documents will be sent out again with the debriefing email when the study closes.

What you will receive for taking part:

Although you will not receive personal compensation, your participation in this study may be able to help a cancer-related organization or cancer hospital ward. To thank you for your participation, you can enter a cancer-related organization or cancer hospital ward of your choice in a draw for a \$100 donation. We will make the donation on behalf of all participants. During the interview, the researcher will ask you if you wish to take part in the compensation draw. If you do want to take part, you will be asked to name a cancer-related organization or cancer hospital ward and its location. If you choose to receive emails about the results of the study, you will also receive an email notifying you of which organization received the donation.

How your information will be protected:

Information that might identify you will be kept private. All of your identifying information will be kept in a separate file, in a secure place. All electronic records will be kept in a password-protected, encrypted file on the lead researcher's personal laptop and external hard drive. In most cases, only the research team will have access to this information. In some cases, other authorized officials at the University such as the Research Ethics Board or the Scholarly Integrity Officer may have access as well. I will describe and share my findings in a thesis, which includes a thesis defence. There is the potential that my findings will be shared at conferences, published in journals, and/or shared with healthcare professionals. I will be very careful to talk only about group results and no information that could identify you will be included in any report or communication. Should I choose to include a quote from you, it will be coded so that your name or other identifying information is not attached to it in any form. This means that *you will not be identified in any way in our reports*. I have an obligation to keep all research information private. I will use a participant number (not your name) in our written and computerized records so that the information we have about you contains no names.

If you decide to stop participating:

You are free to leave the study at any time. If you decide to stop participating at any point during the study, you can also decide whether you want any of the information that you have contributed up to that point to be removed or if you will allow us to use that information. If you would like your information that you have contributed not be used, please contact the lead researcher through the study's email and she will ensure that your information is not used in the study. Your entry into the compensation draw will not be forfeited unless you choose for it to be.

How to obtain results:

We will provide you with a short description of group results when the study is finished should you wish to receive it. No individual results will be provided. You can obtain these results by including your contact information at the end of the signature page.

Questions:

We are happy to talk with you at any time about any questions or concerns you may have about your participation in this research study. Please contact Lisa Fisher (cancer@dal.ca) at any time with questions, comments, or concerns about the research study. Emails will be responded to in a prompt and efficient manner. We will also tell you if any new information comes up that could affect your decision to participate.

If you have any ethical concerns about your participation in this research study, you may also contact the Director, Research Ethics, Dalhousie University at (902) 494-1562, or email ethics@dal.ca

Signature Page

Project Title: Cancer in Emerging Adults: Parents' Psychosocial Challenges

Lead researcher:

Lisa Fisher

MA Health Promotion Candidate, Dalhousie University

Lisa.Fisher@dal.ca

Please type "Yes" or "No" for each of the following questions. If you type "no" to any or all of the following questions, you may still take part in the study; your input is valuable.

I agree that the researcher may re-contact me by email for clarification of any information that I give. _____

I agree to the use of direct quotations in any and all study reports (direct quotations will be coded in the report so that you are not identified). _____

I agree that direct quotations from me may be identified by a fake name assigned by the researcher. _____

If you would like to receive a short description of group results when the study is finished, please type "yes" here. _____

I have read the explanation about this study. I have been given the opportunity to discuss it and my questions have been answered. I agree to take part in this study. I realize that my participation is voluntary and that I am free to leave the study at any time.

Date: Type date here

Signature: Type name here
(By typing your name, you are signing your consent to participate in this study)

*Study correspondence will be via the study's email address: cancer@dal.ca

Appendix G: Debrief

Dear Participant,

I would like to thank you again for your participation in this study.

As a reminder, the purpose of this study is to understand how parents of emerging adult children (those who are between the ages of 18 to 25) with cancer might be challenged by a cancer diagnosis in their young adult child. The data collected during the study will contribute to a better understanding of how parents are affected by the experience of their young adult son or daughter being diagnosed with and dealing with cancer.

Please remember that any information about you as an individual will be kept anonymous and confidential. Once all information is collected and analyzed for this project, I plan on sharing this information with the academic community through a thesis dissertation, publication in academic journals, and conference presentations, as well as with the health care community through a research summary sent to health care professionals and cancer-related organizations throughout Canada. Your individual information will not be used; rather, the collective data of all participants will be analyzed and presented.

If you told me on your consent form that you would like to receive the results of this study, a research summary will be sent to you upon completion of the thesis dissertation. If you are interested in receiving more information regarding the results of this study, or if you have any questions or concerns, please contact me at the email address listed at the bottom of the page.

If you experience any issues you believe come from taking part in this study, please contact me at the email address listed below. Please see the attached sheets to learn about resources and tips that may be helpful for you.

If you have any ethical concerns about your participation in this research study, you may also contact the Director, Research Ethics, Dalhousie University at (902) 494-1562, or email ethics@dal.ca

Lisa Fisher
Lead Researcher
MA Health Promotion candidate
Dalhousie University
Lisa.Fisher@dal.ca
REB File#

Dr. Lynne Robinson
Supervisor
School of Health and Human Performance
Dalhousie University

Appendix H: Organizations for Support

Resources for Parents

Canadian Cancer Society – Helping Someone with Cancer

Information on how you can help someone who has cancer, including visiting someone who has cancer, talking to someone with cancer, how to be a good listener, and helping in practical ways.

Link: <http://www.cancer.ca/en/cancer-information/cancer-journey/helping-someone-with-cancer/?region=ns>

Canadian Cancer Society – If you're a Caregiver

Information on your role as a caregiver, good communication, how to handle appointments, how to give comfort and emotional support, how to give physical care, and looking after yourself.

Link: <http://www.cancer.ca/en/cancer-information/cancer-journey/if-you-re-a-caregiver/?region=ns>

Canadian Cancer Society – Resource Booklets

Links to booklets created by the Canadian Cancer Society that are available to read and print out. Topics include, to name a few, understanding various cancer diagnoses, understanding chemotherapy and other treatments, living with cancer, and what questions to ask the healthcare team.

Link: <http://www.cancer.ca/en/support-and-services/resources/publications/?region=ns>

Canadian Virtual Hospice

Provides support and personalized information about palliative and end-of-life care to patients, family members, health care providers, researchers and educators.

Link: http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx

Cancerview.ca

Connects Canadians to online services, information, and resources for cancer control. It is designed to benefit: people affected by cancer, including patients, survivors, friends, family, and the public; people who treat or care for people affected by cancer; people who work in cancer control or health-care organizations across Canada.

Link:

http://www.cancerview.ca/cv/portal/Home/General_AC/AboutInfo/Cancerview/About?_afrLoop=299960087153000&_afrWindowMode=0&_adf.ctrl-state=fgt8osdv8_85

Cancer Chat Canada

Provides online support to people affected by cancer and is funded primarily through the Canadian Partnership against Cancer. Offers professionally-facilitated online groups that meet once per week for up to 90 minutes in a live “chat” room on the Internet. Most groups meet for 10-12 weeks.

Link: <http://cancerchatcanada.ca>

Cancer Connection

An online community where people facing cancer and their loved ones can share experiences and build relationships to help them through their cancer journey.

Link: <http://cancerconnection.ca>

Cancer Support Community

An international non-profit dedicated to providing support, education and hope to people affected by cancer. Its global network brings the highest quality cancer support to the millions of people touched by cancer. These support services are available through a network of professionally-led community-based centers, hospitals, community oncology practices and online, so that no one has to face cancer alone.

Link: <http://www.cancersupportcommunity.org>

Personal Health Navigator

Paul Taylor, Sunnybrook's Patient Navigation Advisor, will provide advice and answer questions to patients and visitors, relying heavily on medical and health experts.

Link: <http://health.sunnybrook.ca/navigator/>

The Compassionate Friends

Provides highly personal comfort, hope, and support to every family experiencing the death of a son or a daughter, a brother or a sister, or a grandchild, and helps others better assist the grieving family.

Link: <http://www.compassionatefriends.org>

Wellspring

An innovative and growing network of community-based cancer support centres that collectively offer over 50 different programs. Provides support, coping skills, and education at no charge and without need of medical referral to individuals, family members, and professional caregivers living with cancer.

Link: <http://www.wellspring.ca>

Resources for Young Adults

Canadian Cancer Society – Resource Booklets

Links to booklets created by the Canadian Cancer Society that are available to read and print out. Topics include, to name a few, understanding various cancer diagnoses, understanding chemotherapy and other treatments, living with cancer, and what questions to ask the healthcare team.

Link: <http://www.cancer.ca/en/support-and-services/resources/publications/?region=ns>

Cancer Chat Canada

Provides online support to people affected by cancer and is funded primarily through the Canadian Partnership against Cancer. Offers professionally-facilitated online groups that meet once per week for up to 90 minutes in a live “chat” room on the Internet. Most groups meet for 10-12 weeks.

Link: <http://cancerchatcanada.ca>

Cancer Connection

An online community where people facing cancer and their loved ones can share experiences and build relationships to help them through their cancer journey.

Link: <http://cancerconnection.ca>

Cancer Fight Club

Aims to provide adolescent and young adult patients and survivors, caregivers, family and friends, instant access to the resources and support services that help guide you through your cancer experience.

Link: <http://www.cancerfightclub.com>

I Had Cancer

A cancer support community that empowers people to take control of life before, during and after cancer. Members can search by type of cancer, age, gender, location, year of diagnosis and type of user so that they can easily find others who have experienced their specific situation.

Link: <http://www.ihadcancer.com>

Survive and Thrive Cancer Programs

Uses adventure expeditions, film, healthy living, experiential education and research to encourage and inspire those touched by cancer to live well.

Link: <http://survivethrive.org>

TeamShan

Purpose is to educate the public, health care professionals and young women about early detection, risk reduction and prevention of breast cancer.

Link: <http://www.teamshan.ca>

Wellspring

An innovative and growing network of community-based cancer support centres that collectively offer over 50 different programs. Provides support, coping skills, and education at no charge and without need of medical referral to individuals, family members, and professional caregivers living with cancer.

Link: <http://www.wellspring.ca>

Young Adult Cancer Canada

Mission is to build a community of young adults diagnosed with cancer that provides information, support, skills, and opportunity.

Link: <http://www.youngadultcancercanada.ca>

Appendix I: Tip Sheet: Caring for Yourself

When faced with a cancer diagnosis of someone close to you, it can impact your life significantly. Sometimes, parents resume the caregiving role when their young adult son or daughter is diagnosed. It is important that you ensure that you are taking care of yourself throughout your experience. If you have better physical and mental health, you will be more able to provide optimal care to your son or daughter.

Understand Your Feelings

- Sadness – If you feel sad, that is okay. If you are feeling overwhelmingly sad for more than two weeks and you have stopped taking part in activities that you used to enjoy and/or are unable to carry on with your daily tasks, you may be depressed and it is important that you seek out professional help.
- Anger: You may experience anger with yourself, your family members, your friends, and/or the general public. You may be angry with your son or daughter. If you are angry, try to understand why you are.
- Grief: You may be feeling loss for the life you used to lead, or for the life your son/daughter used to have. Let yourself grieve these losses and know that it is okay.
- Guilt: Feeling guilty is common. You may think that you are unable to help as much as you feel that you should or you may feel guilty that you are healthy and your son/daughter is not
- Loneliness: You may feel lonely, even when you are surrounded by people.

What Can I Do?

- Talk to someone. Whether this be a professional, a family member, a friend, or your pastor/minister, talking about your feelings and emotions will help you deal with them better
- Join a support group
- Know that we all make mistakes and that you are not required to be perfect
- Cry or express your feelings. You do not have to pretend that you are okay
- Do not try to do everything. Focus on the important, big things in your life at the moment
- Remind yourself that you are doing the best you can
- Spend some time alone to reflect
- Use relaxation techniques, such as deep breathing or meditation
- Pray or meditate
- Write down your feelings in a journal

Ask Others for Help

Who Can I Ask for Help?

- Family
- Friends
- Neighbors

What Can I Ask them to Help Me With?

- Cooking
- Cleaning
- Shopping
- Yard work
- Childcare
- Eldercare
- Be a listening ear
- Lend their vehicle or their time to drive to doctor visits
- Find information that you need
- Relay information about how your son/daughter is doing to others

Look After Yourself

- Make healthy meals and try to eat on a regular basis
 - If you are having difficulty making meals, ask one or more people if they would mind making some meals to freeze for you and your family
- Be physically active on a regular basis
 - Even if you go for a short walk, try to be physically active at least once a day
- Have regular physical examinations and dental checkups
 - If you notice that something is wrong or suspicious with your health, go to your doctor; do not put it off
- Get enough rest
 - Sleep when your son or daughter is resting or sleeping
- Take time to relax and do the things you enjoy

Coping tips

- Find out information from your healthcare team or caregiver groups on caring for your loved one.
- Break big problems or tasks into smaller ones to make them easier to manage
- Set aside time for other loved ones and friends
- Take a break
- Pamper yourself in little ways
- Join a caregivers group or another support group

Adapted from:

National Cancer Institute (Caring for the Caregiver)

<http://www.cancer.gov/cancertopics/coping/caring-for-the-caregiver>

Canadian Cancer Society (If you're a Caregiver)

<http://www.cancer.ca/en/cancer-information/cancer-journey/if-you-re-a-caregiver/?region=ns>

Appendix J: Explanation of Change in Method

The original study design was to have between 15 to 30 participants Canada-wide who would take part in the online focus group and answer the questions I had posed as the researcher, while also interacting with other participants. As a result of low enrolment and recruitment issues, an ethics amendment was sought and approved to change the methodology to an exploratory collective case study approach requiring only two to four cases. In addition to requiring fewer cases than the original design, the case study approach allowed me to explore each participant's experience more in depth than I may have been able to through the asynchronous focus group.

Recruitment methods were also changed. Both Facebook and Reddit were used until the change in methodology from an online focus group to a case study approach; after which they were discontinued as research methods.

Data were originally to be collected through an online discussion-based focus group using Blackboard Learn, a platform created by Blackboard as an enhanced learning management system. The Instructional Technologies Department at Dalhousie University created the Blackboard Learn sites, which they referred to as "online learning communities", and provided a list of user accounts with randomized account numbers that I used to enrol participants. Demographic information was acquired through the survey tool on Blackboard Learn, and the online focus group was conducted using the discussion board on the online learning community. The focus group was asynchronous and consisted of semi-structured questions. There was also an area on the online learning community where I uploaded documents for participants to view.

Appendix K: Glossary

Children

Children refers to those who are between the ages of 0 and 15. In this study, emerging adult children will be referred to as “EA children”.

AYA

Adolescence and young adulthood are often grouped together in research and, sometimes, in medical practice and given the acronym “AYA”. The National Cancer Institute (n.d.) in the United States defines AYA as those individuals between the ages of 15 to 39. In Canada, AYA is most often defined as those between the ages of 15 to 29 (Canadian Partnership Against Cancer, n.d.). Depending on what age range the authors looked at within their study, the background literature on AYA represents either the 15 to 39 age range or the 15 to 29 age range.

Emerging Adults

Emerging adults are those between the ages of 18-25 (Arnett, 2000). These individuals experience a series of unique challenges given their developmental phase. This is a population who has surpassed adolescence, yet have not reached the pinnacle of adulthood. They have achieved a delicate independence and are on a journey to complete their self-identities, create important relationships, find their professional calling, and prepare themselves for attainment of full-fledged adulthood.

Parents

Within the current study, parents are those who are genetically related or adoptive parents, or are step-parents. Parents from both opposite-sex and same-sex partnerships/families were able to be included. All parents from a particular family were

entitled to take part in the study. Each participant was asked to identify whether or not another parent of their child was taking part in the study, to the best of his/her knowledge.