

**QUALITY OF LIFE CONCERNS IN YOUNG ADULT SURVIVORS OF  
CHILDHOOD CANCER: A QUALITATIVE RESEARCH INVESTIGATION**

A Dissertation

by

STEVIE LANE PUCKETT

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Co-Chair of Committee,	Jan Hughes
Co-Chair of Committee,	William Rae
Committee Members,	James Varni
	Robert Heffer
Head of Department,	Victor Willson

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## ABSTRACT

Although young adult (YA) survivors of child cancer comprise a unique group from a developmental standpoint, in most treatment and research settings either child or general adult measures of quality of life (QL) are used to measure adjustment and functioning. Studies have relied heavily on survey methods, and though many hint at a variety of specific problems that a subset of YAs may experience, most identify YA survivors as relatively well adjusted. Interview studies with survivors and care-providers and interactions in survivor support venues paint a more complex and problematic picture of adjustment. To better understand the QL concerns unique to YAs this study employed grounded theory methodology to build a model of survivorship from participant perceptions. Four focus groups were conducted (N=15) with survivors between the ages of 18 and 30 years recruited from in-person and online support group settings. Themes emerged describing a larger extent of struggles than prior studies have identified. The grounded theory model detailed that having cancer can fundamentally change an individual, and these changes and resulting struggles do not end with remission. Survivors described constantly pursuing normalcy in the context of being fundamentally different, while balancing the dual roles of *young adult* and *survivor*. Survivors revealed difficulties in essentially every area of their lives (school, work, friendships, family, romance, self-esteem, outlook and attitudes, etc.), and though many could identify strategies for addressing these problems, maladaptive coping techniques dominated and survivors were left feeling overwhelmed, under-supported, and misunderstood. Results

suggest that YAs could benefit from QL measures developed specifically with their unique concerns in mind. While progress has been made in developing YA-specific measures, such measures have not become widespread practice in clinical and research settings. Furthermore, this study suggests that collecting such information in a conversational, semi-structured interview format may elicit a fuller scope of survivors' concerns than pencil and paper methods, though further research is recommended in this area.

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## CHAPTER 1

### INTRODUCTION

Child cancer survival rates have dramatically improved with the rapid progress and development of treatment methods in recent years, calling attention to survivorship issues in research. In the 1960's most children with cancer died, with less than 20% surviving (Miller & McKay, 1984). Currently, almost the exact inverse is true, with survivorship boasting a rate of almost 4 in 5 children (78-80%) diagnosed with cancer beating the disease, according to the latest national incidence reports through 2009 (NCI, 2010; NCI, 2012). Approximately 1 in 900 adolescents and adults are survivors of pediatric cancer (Barkon, 2009), and in the coming decades it is projected that that number will double (Bleyer, 2005). There have been excellent advances in cancer care, particularly with the introduction of CNS prophylaxis, multidrug regimens, delayed intensification of chemotherapy, the use of maintenance intrathecal methotrexate, and targeted proton therapy (Askins & Moore, 2008). These revolutions in treatment have contributed to vastly improved survival rates for both children and adults, which affords us the fortunate opportunity and responsibility of turning our attention to issues related to survivorship. With this shift in focus comes a wealth of research on social, emotional, and behavioral outcomes for cancer survivors, and the birth of the rapidly evolving field of psycho-oncology.

As the field of survivorship expands, we are finding that there are gaps in our knowledge, particularly when it comes to adolescents and young adults. Much of what we know about survivorship suggests that overall, cancer survivors do not have

significant mean differences from the general population on many standardized psychological tests, and exhibit healthy psychosocial adjustment, suggesting that cancer truly can be “beaten” on more than just a physical level (Patenaude & Kupst, 2005). However, more subtle and specific problem areas have been identified in long-term survivors, with studies noting that a small but significant subset of cancer survivors *are* at risk for particular sub-clinical negative outcomes such as poor adjustment and adaptation, higher levels of posttraumatic stress symptoms, and increased worries, among other concerns (Hobbie, Stuber, & Meeske, 2000; Kazak et al., 2001; Langeveld, Grootenhuis, VoUte, de Haan, & Van do Bos, 2004). It is difficult to identify exactly which subsets of survivors experience problems and to what extent as measures and sample characteristics have varied across studies. To compound the problem, it would seem that outlets that have not relied on survey-style inquiry, such as clinicians’ reports, forums, support groups, and interviews with survivors reveal more adjustment difficulties than even the varied research would suggest (Enskar & Bertero, 2010; Odo & Potter, 2009). Considering the havoc that cancer and resulting treatments such as chemotherapy and radiation can wreak on a person’s physical, emotional, and mental well-being, as well as the late-effects that can occur in long-term survivors, it is not surprising that some individuals are at high risk for poor psychosocial adjustment. Though survivorship and quality of life studies have not been able to come to agreement on exactly what difficulties exist and for whom, most studies have consistently demonstrated that adjustment difficulties appear to be most evident in (a) individuals who have reduced health and physical functionality as a result of their disease course

and aggressive treatment and (b) those that are in the adolescent or young adult age range, and there are many correlates that contribute to whether or not a particular survivor will have adjustment problems.

Many studies highlight that when child cancer survivors reach adulthood they can experience a plethora of problems related to schooling and employment, insurability, ability to get married and have children, obtaining independent living, and the establishment of stable relationships with family and friends (Boman & Bodegard, 1995; Boman, Lindblad, & Hjern, 2010; Langeveld, Ubbink, Last, Grootenhuis, VoUte, & DeHaan, 2002; Madan-Swain, Brown, Foster, Vega, Byars, Rodenberger et al., 2000). These difficulties tie into and may both influence and be influenced by quality of life. Furthermore, young adults may experience these difficulties to a greater degree than any other age group (Hobbie et al., 2000). Additionally, studies have shown that older adolescents and young adult survivors are more likely to have avoidant coping styles and/or be quicker to foreclose on their identities than any other age group and fail to achieve individuation compared to healthy controls (Madan-Swain et al., 2000).

Knowing that young adult long-term survivors of pediatric cancer are at the most risk for poor outcomes such as those mentioned above highlights the importance of adequate screening measures for patients who may be experiencing such problems or are in need of additional support. The most common method of assessing quality of life or, life satisfaction across domains, in individuals is by questionnaire or survey formats, which are typically dichotomously divided between child/adolescent and adult measures (Beck, 2010). Though progress has been made in adapting measures for use specifically

with young adults, hospitals, clinics, and researchers often give young adults the child or adolescent versions of the quality of life measures or more generic adult measures. The most common practice still appears to be relying on modified child or adolescent measures. This practice is likely because young adult child cancer survivors can have more in common with their younger adolescent counterparts than other adults their age (or older adults); issues surrounding treatment, recovery, and survivorship can require young adult patients to have a continued reliance on their parents and families, and therefore experience delays and difficulties in achieving the milestones of adulthood. Often, patients who undergo treatment during childhood for pediatric cancer choose to continue their follow-ups and related services within the pediatrics department rather than transitioning to adult services. Such factors contribute to treatment of young adults closely resembling the treatment of pediatric patients. The PedsQL™ is an excellent example of a child and adolescent Health Related Quality of Life (HRQL) measure that has been adapted for use with both young adult cancer survivors and older adults. Ewing, King, and Smith (2009) found that after making minor alterations to the wording of the PedsQL™ Generic Core and Cancer Module for teenagers and administering the adapted measure to adolescents and YAs 16-25 years of age the measure maintained its hypothesized factor structure and was able to discriminate symptoms between groups. The only changes that were made to this adapted measure included adding the word “work” to the school-based items and using the term “young adult” rather than teen. This same adapted pediatric measure was used with older adults between 25 and 40 years of age with similar findings and was deemed feasible and valid, though ceiling effects were

noted in particular areas (Robert, Paxton, Palla, Yang, Askings, Joy, and Ater, 2012). Though such adaptations have been a step in the right direction, they are not the best or most comprehensive approach to learning about the needs of YAs. Knowing that an adapted measure has similar factor loadings (construct validity), can discriminate between groups (discriminant validity), and had minimal items left blank (feasibility) does not tell us whether or not important factors are missing or whether the adapted items are truly developmentally relevant. Domain specific studies of survivors have found concerns in relationship satisfaction, likelihood to marry or date, problems with individuation, sexual functioning, and so on, and such concerns are not adequately addressed in adapted child measures; thus, more work continues to be needed in identifying a better approach for YAs.

As young adults are one of the most vulnerable of pediatric cancer survivors, one would expect that survivors in this age range (18-30 years) would evidence poorer ratings on generalized measures of adjustment. However, many studies using quality of life surveys have found that young adult pediatric cancer survivors do *not* report overall worse adjustment scores than the general population (Eiser, Hill, & Vance, 2000). At least two explanations for this unexpected finding are plausible; either young adult survivors truly are functioning adequately compared to healthy controls and do not experience more challenges related to QL, *or* the measures that are frequently used are not tapping into the unique concerns and challenges that survivors in this age group may face. If the second explanation holds, more information and research on young adult survivors' needs is in order. There is also a plausible third alternative; it may be the case

that something about the process or method of measurement of psychosocial constructs in young adult survivors precludes the elicitation of the full range of survivors' concerns or problems. Considering that survivors have been found to have avoidant or repressive coping styles, in conjunction with survivor reports of not feeling as though their problems would be understood by healthy individuals, it could be that survivors are not likely to report the depth of their concerns on written measures and that other methods could be more effective or successful at eliciting a fuller picture of their concerns. It would be particularly valuable to glean survivors' perspectives in regards to these concerns.

Whereas we have more child cancer survivors than ever, and those child patients grow into young adult survivors with new developmental needs and concerns, our health care system is starkly divided between pediatric and adult care, leaving young adults without a home, so to speak. This dichotomy leads to young adults being lumped in with standard child or adult care (Beck, 2010). The problem with this 'tag-along' approach is that there is ample evidence suggesting that this group differs greatly from children and older adults, and thus presents unique needs that may not be addressed by developmentally insensitive measures (either child or adult) and service provision. There is a need to better understand quality of life and adjustment in YA survivors so that effective interventions can be developed in order to prevent or ameliorate adverse outcomes such as late effects complications (Aziz, 2002). To better understand the discrepancies in the research surrounding young adult survivors' experiences it is necessary to take a step back and go to source of those experiences, survivors

themselves. It can be useful to set aside *a priori* orientations or expectations and bring survivors' voices into the literature in order to gain a clearer understanding of what problems and concerns they perceive as relevant and meaningful. This dissertation seeks to explore the quality of life concerns of young adult long-term survivors as a unique developmental group. It may be the case that YAs would benefit from targeted measures of quality of life that explore a more rich range of developmentally appropriate factors than do most current measures, more diverse methods of collecting such information, or from different methods of care and support. A focused review of the literature is provided in chapter two, setting the stage for the grounded theory study outlined in chapter 3. This study employs qualitative focus group methodology to define the areas of concern for YA survivors and develop a model that captures and explains those areas and experiences, as survivors themselves perceive them. Results and Discussion sections will be included in chapters 4 and 5.

## **CHAPTER II**

### **REVIEW OF THE LITERATURE**

#### **Pediatric Cancer**

According to the National Cancer Institute (2008), child cancer is the leading cause of death by disease among children in the United States, although it is still considered “rare”. The National Cancer Institute (2011) defines cancer as a disease in which abnormal cells continuously divide without control and invade other tissues, traveling to other parts of the body by the blood or lymph systems. Cancer is a term used to signify not just one disease, but over a hundred. The most common types of child cancers include those of the blood or central nervous system, such as leukemia or brain tumors. Together, Acute Lymphocytic Leukemia (ALL) and CNS cancers comprise approximately 95% of child cancers (Butler & Haser, 2006), though teens and young adults are more likely to get certain other cancers, such as those of the bone or lymphomas. Child cancer treatment was once strictly the realm of medical doctors, with very little professional psychological services or support provided. Fifty years ago, the spirit of treatment was such that information about their disease was not openly discussed with the child patient, as it was thought that children could not understand or cope with the knowledge that they might die. Researchers began to discover that children possessed adequate ability to process and cope with the information, and generally demonstrated more favorable adjustment when allowed to participate in their own medical planning and decision-making (Patenaude & Kupst, 2005). With these new discoveries, trends in service delivery shifted to include the child, opening up the doors



for the inclusion of mental health professionals. Moreover, as thinking about the child patient expanded beyond physical symptoms to holistically include social, emotional, and psychological needs, a new paradigm of comprehensive service provision was defined (Patenaude & Kupst, 2005).

### **Pediatric Psycho-oncology**

With this shift to more holistic cancer care came the introduction of pediatric psycho-oncology, the study of the psychological components of the experience of child cancer and cancer care. Over the past 30 years, the field of psycho-oncology has greatly evolved, following a scientist-practitioner model of providing clinical care, psychological assessment, and research to advance knowledge of children's psychosocial adaptation to treatment and survivorship (Askins & Moore, 2008). Pediatric psycho-oncology has provided insight into the behavioral and psychological functioning of pediatric cancer patients and their families (Patenaude & Kupst, 2005). This shift has broadened the scope of treatment, expanding beyond the sole doctor-patient relationship to include a variety of competent, care-oriented individuals collaboratively working together on the patient's medical team (Askins & Moore, 2008). Not surprisingly, as psycho-oncology evolved and communication and inclusion improved, so did overall child cancer treatment, along with patient survival rates. The field of psycho-oncology allows us to better understand the effects of cancer on children's mental and emotional well-being, and how those effects contribute to disease prognosis and future survivorship.

Although a cancer diagnosis is no longer the death sentence it once was, the diagnosis, treatment, and survival of cancer is one of the most difficult obstacles a child and his or her family can encounter. Most children and families report that receiving a diagnosis of cancer altered everything about their lives, including school, friendships, finances, family roles, and life outlooks. It is clear that such a collection of life-altering changes has the potential to impact a child's coping ability and long-term quality of life.

### **Treatment and Treatment Effects**

Cancer treatment can often pose just as many risks and challenges as the disease itself. Cancer can be treated with a variety of methods, which most commonly include: medication, chemotherapy, radiation, surgery, transplants, or any combination of these or others depending on disease location and type (NCI, 2011). Treatments can be quite painful and produce a host of negative side effects.

Chemotherapy ("chemo") is one of the most common treatments used, and works by administering a drug regimen that kills fast-growing cancer cells. However, in children even healthy cells are fast-growing; therefore these powerful drugs inadvertently damage normal-functioning, healthy cells as well, disrupting necessary growth for 'good' cells. The short term side effects of chemo include low blood cell counts, nausea, diarrhea, and hair loss, though the severity and likelihood of these depends on the type and dosage of the drug.

Radiation therapy is another common treatment approach, which may be used in conjunction with other methods, or as the primary treatment. Radiation therapy employs high energy rays to shrink tumors and kill cancer cells. Much like chemotherapy,

radiation can kill normal cells as well, and cause a variety of short-term side effects such as organ failure, secondary illnesses, and cognitive or behavioral impairments.

Even some of the most basic tests for cancerous cells are extremely painful and distressing. Bone Marrow Aspirations (BMAs) and Lumbar Punctures (LPs) are invasive tests that are frequently used to monitor the presence of cancerous cells and the effect of treatment on the body. BMAs are performed by injecting a very large hollow needle into the pelvic bone in order to draw out a sample of bone marrow for testing (Jay, 1985). LPs, or ‘spinal taps’, involve a similar injection into the base of the spine in order to extract cerebrospinal fluid (CSF) for testing. Many children are subjected to such tests over 50 times throughout the course of their disease treatment (Jay, 1985). Whereas some treatment facilities use full anesthesia to protect individuals from the pain and trauma of the experience, it is still common procedure in most hospitals and clinics for children to undergo these procedures with minimal medication (Blount, Piira, Cohen, & Cheng, 2006).

It is evident that this very aggressive disease requires an equally aggressive treatment response that can be painful and cause nasty side effects, leaving the patient to fight not only the challenges of their cancer, but the challenge of their cancer *treatment* as well. These difficulties do not merely impact the child’s life as a patient, but can have far-reaching implications further down the road into survivorship as well.

### **Survivorship**

Individuals are classified as achieving long-term survivorship when they are two to five years or more into remission, meaning they are cancer-free. There are

approximately 270,000 survivors of pediatric cancer in the United States (Askins & Moore, 2008). Although these individuals are expected to live normal life spans after “beating” their cancer diagnosis, the battle is not over—they face the possibility of future risks and difficulties related to being a long-term cancer survivor. The term “late effects” is ubiquitous in survivorship literature.

### **Physical Late Effects**

With improved survival rates we have been able to look at how cancer and its related treatments can affect survivors long-term, and the field of late effects has burgeoned. Late effects are problems or complications that may not show up during or directly after treatment, but are effects whose presence is not made known until months, years, or even decades later (ACS, 2010). Such effects are quite common, with as many as two-thirds of childhood cancer survivors experiencing at least one late effect, and one-fourth of survivors reporting a late effect that is severe or life threatening (National Cancer Policy Board [NCPB], 2003). Over 25% of deaths in survivors of child cancer can be attributed to treatment-related late effects (Sklar, 1999), and these factors may be compounded by lifestyle behaviors such as smoking or drinking, which may be engaged in more frequently by survivors (Lansky, List, & Ritter-Sterr, 1986; Nolen-Hoeksema, 1987). Late effects most often are related to the types of treatment that were used; chemotherapy, radiation, and surgery are the main culprits of late effects.

Physical late effects from aggressive treatments cover a wide range of body parts and systems. Heart problems, lung problems, organ failure, healthy tissue damage, functional mobility deficits, infertility, sensation and perceptual deficits, and dental

problems are just a snap shot of the problems that survivors may encounter (ACS, 2011). Survivors are also at a higher risk for developing secondary cancers in their lifetimes, or having recurrences after remission (Mertens et al., 2001). One common physical late effect that could affect psychological, emotional, and relationship functioning is infertility. Infertility is likely a concern that is particularly relevant to young adults (18-30 years). Zebrack & Zeltzer (2003) point out that given what we know about infertility effects in young adult survivors, we still lack an understanding of exactly how this complex late effect affects quality of life, including attitudes about having children, worries about children being at a higher risk for cancer, and so on. This is just one of many late effects that are likely to be most pertinent to young adults. Beyond physical concerns, late effects that reduce the neuropsychological and cognitive functioning of survivors are garnering attention in research.

### **Cognitive and Academic Declines**

Ample research indicates that both the disease and its treatment can affect higher-order cognitive functioning and academic performance; in fact the experience of neurocognitive deficits is the most commonly reported late effect in survivors (NCPB, 2003). In a review of late effects, Friedman and Meadows (2002) detailed that neurocognitive deficits for pediatric survivors can be quite pronounced, particularly for those having received chemotherapy or cranial radiation, with the average child survivor experiencing a 5-14 point decline in Full Scale Intelligence Quotient (FSIQ). Increased amounts of radiation therapy and intravenous chemotherapy have shown particularly deleterious effects, with negative correlations between dosage and frequency of

radiation/chemotherapy and attention, nonverbal memory, visual-spatial functioning, and fine motor abilities (Butler & Hasler, 2006). In a series of studies on late effects, Copeland (1985, 1988a, 1988b) identified non-dominant cortical functions as being maximally effected by cranial radiation; problems such as performance intelligence, math skills, processing speed, visual-motor integration, and non-verbal reasoning are most likely to persist, whereas verbal abilities and expressive functions tend to be unaffected. Expectedly, academic achievement is affected, with overall declines in grades and participation noted, as well as higher rates of academic failure and learning disabilities (Palmer, 2007). In a study of 800 child cancer survivors, Barrera (2005) found that compared to matched controls, survivors are more than twice as likely to repeat a grade and have poorer achievement, be labeled as Learning Disabled (LD), or report general problems or difficulties with education and school. Educational difficulties were most evident in survivors of CNS cancers, Leukemia, and Neuroblastoma, which together make up the majority (over 95%) of all child cancers, though non-Hodgkins lymphoma and primary bone cancers are increasingly contributing to the prevalence of cancer in older adolescents. The intensity of the treatment (cranial radiation) was positively related to the likelihood of having educational difficulties. Similar results were noted in an evaluation of 12,430 survivors in the Childhood Cancer Survivor Study (CCSS); 23% of survivors reported using special education services compared to 8% of sibling controls (Mitby, Robison, Whitton, Zevon, Gibbs, Tersak, Meadows, Stovall, Zeltzer, & Mertens, 2003). They found that individuals with CNS tumors and those who had higher doses of intrathecal methotrexate and/or cranial

radiation were most likely to utilize SPED services. Over 70% of brain tumor survivors treated in early childhood required special education services, and almost 1 in 5 18- to 24-year-old brain tumor survivors did not complete high school. This study found that, overall, survivors who had CNS tumors, leukemia, non-Hodgkins lymphoma, and neuroblastoma were less likely than to complete high school compared with siblings, regardless of types of treatment. Even survivors of non-CNS cancers have shown educational difficulties, with one study by Gerhardt et al. (2007) finding that non-CNS cancer survivors are significantly more likely to be retained in grade than are healthy peers. In an early study of survivors' worries, Moore et al. (1987) found that almost all cancer survivors who had academic difficulties and failure to some degree attributed those difficulties to their history of disease and treatment.

Academic struggles can also follow young adult survivors to college. Interviews with college-bound survivors and their treatment providers and family members indicated that individuals with neurocognitive deficits may be more likely to pursue a vocational trade rather than attend a full college or university, and those who do attend a full university may experience a variety of difficulties related to the adjustment of having less supports and external structure, and this lack of structure and support can lead to poorer grades and performance and increased frustration (Moll, 1998).

### **Employment and Insurability**

Additional areas of concern include employment and insurability, both of which are frequently listed as top worries for survivors. A study from Langeveld et al. (2004) revealed that young adult cancer survivors worry more about getting or changing jobs

and the ability to be insured through those jobs than their same-age healthy peers; furthermore, such employment and insurability worries predicted worse quality of life ratings in these survivors. It turns out that these worries are not without merit as studies have shown higher unemployment rates in child cancer survivors than healthy control groups. Pang et al. (2008) reviewed a large sample of survivors in the Childhood Cancer Survivor Study (CCSS), a nationally funded research study of late effects in survivors. Self-reported employment history of 10,399 child cancer survivors and their healthy siblings was examined. It was found that survivors were at a significantly higher risk for unemployment with 5.6% reporting that they had never been employed compared to 1.2% of their healthy peers. Rates of unemployment as measured by just the preceding year also were in the favor of the healthy controls, with survivors more than one third more likely to have been unemployed for the past year than their siblings. Similar studies have identified that young adult survivors are less likely than their healthy peers to be employed, and more likely to be living at home (with parents) (Boman et al., 2010; Langeveld et al., 2002). Furthermore, an earlier study found that cancer survivors are more likely to foreclose on their employment options and career directions (Stern et al., 1991). Such results suggest that employment and insurability worries in young-adult survivors are reasonable concerns that can affect quality of life and well-being, and that future and career planning can be challenging for survivors.

### **Psychopathology**

Another potential problem in child cancer survivors is psychological and emotional health, and research pertaining to these areas has returned mixed results.



Though some smaller studies report elevated levels of depression and anxiety, most studies have found that cancer survivors are not at higher risk for developing clinical syndromes of depression or anxiety. In an exploration of over 5,000 cancer survivors from the Childhood Cancer Survivor Study (CCSS), Zebrack and Zeltzer (2003) found that rates of clinical depression in the survivors were comparable to rates in the general population. Although clinical depressive and anxious disorders not necessarily more likely, *subclinical* levels of depressive or anxious symptoms are frequently noted.

Multiple studies using samples of survivors from the Childhood Cancer Survivor Study (CCSS) have found that survivors do indeed report more symptoms of psychological distress than sibling controls. It was found that using a subsample of 5736 CCSS participants, survivors of leukemia, Hodgkin's disease, and non-Hodgkins lymphoma were significantly more likely to report symptoms of depression and somatic distress (Zebrack, Zeltzer, Whitton, Mertens, Odom, Berkow, & Robison, 2002). Similarly, in reviewing 9, 535 young adults in the CCSS, Hudson et al. (2003) identified 17% of the survivors as having depressive, anxious, or somatic symptoms, which was an odds ratio of 1.8, significant at a p value of less than .001. Further study with a sample of 1101 survivors taken from the CCSS identified that when accounting for demographic, economic, and health-status variables, survivors of childhood brain cancer report significantly higher depression and global distress scores than a sibling control group (Zebrack, Gurney, Oeffinger, Whitton, Packer, Mertens, Turk, Castleberry, Dreyer, Robison, & Zeltzer, 2004). When looking at the Brief Symptom Inventory (BSI) for psychological distress, approximately 22% of long-term survivors of childhood cancer

exhibit “caseness for distress”, which has been relatively consistent in relation to estimates of 20-32% across studies (Zebrack & Landier, 2011).

A frequent finding for studies exploring psychopathological concerns in young adult survivors is the presence of post-traumatic stress symptoms (PTSS). PTSS are symptoms and features of the broader disorder of Post-Traumatic Stress Disorder (PTSD). PTSD is identified by the DSM-IV TR (APA, 2000) as an anxiety disorder whose essential feature “is the development of characteristic symptoms following exposure to an extreme traumatic stressor” that can involve the threat or probability of death, harm, or insult to oneself or a loved one (p. 463). Cancer is conceptualized as a traumatic event because survivors repeatedly must re-experience stressful psychological aspects of the disease, treatment, and after-effects (Kazak et al., 1997). Both adolescent and young adult survivors report moderate-to-severe PTSS symptoms more frequently than the normative population; however, young adult survivors have a markedly increased risk of developing PTSD, more so than any other age group. Hobbie et al. (2000) surveyed 78 young adult survivors of child cancer to find that over one-fifth of them met the American Psychiatric Association’s criteria for PTSD, with clinically significant levels of intrusive and avoidant symptoms, and elevated state and trait anxiety, as well as higher perceived threat and psychological distress. The one-fifth estimate of young adult survivors having moderate-to-severe PTSS has been a consistent finding across studies (Erickson & Steiner, 2001; Kazak et al, 2001; Meeske, Ruccione, Globe, & Stuber, 2001), indicating that stress symptoms are a significant concern for young adult survivors. Additionally, elevated reports of stress symptoms have been

found to be related to the development of identity in survivors (Madan-Swain et al., 2000) and with lower health-related quality of life (Meeske et al., 2001).

### **Identity and Coping**

Stage theory of identity development recognizes a developmental continuum of identity stages that individuals may traverse. Madan-Swain et al. (2000) investigated identity formation, family functioning, life stress, and anxiety among cancer survivors and a healthy comparison group. They found that a significantly higher number of the cancer survivors were in foreclosed identity status, which was consistent with previous research indicating that cancer survivors prematurely foreclose on career decisions (Stern, Norman, & Zevon, 1991). A foreclosed identity status indicates that an individual has not actively explored or questioned alternatives; rather the individual has made a premature decision and strong commitment to one position which they will defend. Survivors were more likely to remain in the foreclosed identity stage and exhibit a reluctance to take risks, preferring to rely heavily on the opinions of others. The authors explained that due to the cancer experience, survivors may have had to foreclose on their options for a variety of reasons which may have served a protective role, and this experience may have carried over to being more reluctant to risk exploration of alternative options and value systems in more general situations. Furthermore, it was found that symptoms of PTSD in survivors were associated with being in the foreclosed identity status.

In conjunction with cancer survivors being more likely to foreclose on their identities and alternatives, data suggest a tendency to employ avoidant coping styles.

Phipps and Srivastava (1997) demonstrated that survivors are more likely than healthy peers to have a repressive style of adaptation and to minimize distress or repress or avoid dysphoric feelings. Similarly to foreclosing on options, this style of repressive and avoidant coping may have served a protective function in helping the patient cope with the disease, treatment, and late effects. Madan-Swain et al. (2000) posited that the data on cancer survivors may commit and internalize the belief systems of others in order to “not have to deal with the uncertainty and ambiguity of exploring future alternatives” (p. 113). It is clear that survivors may deal with stressors of survivorship by being more likely than their healthy peers to foreclose on their identity and avoid or repress their feelings related to their experience of cancer. Regarding coping, studies have also indicated that when it comes to coping with the stressors of their disease, patients do not habituate to the stress, and coping does not improve with time (Dahlquist et al., 1985; Jay, 1985). However, Evans and Zeltzer (2006) did find that the older an individual is at the time of diagnosis the more likely he or she is to have a perceived sense of control, which can be beneficial in coping with the stressors of cancer. In sum, survivors have difficulties with achieving healthy development in both identity formation and coping skills, and instead may rely heavily on external supports and structure to supplant the need to independently come to conclusions and make decisions. Survivors’ tendency for avoidance or repression may be problematic when trying to measure adjustment difficulties; survivors could potentially have more difficulties than measures might suggest.

## **Survivor Beliefs**

Understanding the worries of cancer survivors is important for two reasons. First, worry has been shown to be an important component of adjustment, and second, the self-reported worries of survivors can provide information for developing effective supports (Langeveld et al., 2004). Compared to healthy young adults, young adult cancer survivors report having more worries about a relapse, fertility, health of future children, employment, and insurability (Langeveld et al., 2004). The authors noted that surprisingly, survivors experience less worry than healthy controls about basic health problems like getting a cold or the flu, as well as worrying less about death, their parents' health, and losing friends. This finding may be due to the frequent experience with and adjustment to such issues throughout their disease and treatment. Regarding friendships, it should be noted that although survivors do not report worries about friends or frequent social concerns, Barrera (2005) found that survivors were less than half as likely as their healthy peers to have close friends and to use friends as confidants. Many of the worries that survivors do report having are more cancer specific, according to Weigers et al. (1998). Consistent with the Langeveld et al. (2004) study, Weigers et al. (1998) found that survivors worried less about general concerns such as minor daily health concerns and family members' welfare. Zebrack and Chesler (2001) found that survivors were more likely to worry about cancer-specific concerns, although they also reported being moderately concerned about being as healthy as others their age. It appears that the types of worries that survivors have are not frivolous, but closely mirror

problems that they are actually likely to have as a result of their cancer experience, such as employment and insurability concerns, fertility issues, and cancer recurrence.

Researchers suggest that having elevated worries and concerns can affect self-concept and self-esteem, which can be troublesome as a positive self-concept is regarded as a basic psychological need (Erikson, 1950; Langeveld et al., 2004). Contrary to expectations, the ‘typical’ cancer survivor does not report having worse self-esteem than the average healthy young adult. In a study of 400 long-term survivors of childhood cancer who completed the Rosenberg Self-Esteem Scale, no significant mean differences were found in self-esteem scores between survivors and healthy controls, though for the survivors who did endorse low self-esteem, low ratings were found to predict worse quality of life (Langeveld et al., 2004). Similarly, reports of low self-esteem and poor self-concept are related to increased risk-taking behaviors (drinking alcohol, smoking tobacco, less likely to exercise, etc.), as well as reduced quality of life in both male and female survivors (Lansky, List, & Ritter-Sterr, 1986; Medical News Today, 2009; Nolen-Hoeksema, 1987). Overall, regardless of general psychosocial health, most studies find that when survivors report having problems with late effects, learning problems, or worries about relapse, they are more likely to endorse lower self-esteem and reduced quality of life scores (Zebrack & Zeltzer, 2003). It should be noted that although cancer survivors do not generally report self-esteem or self-concept problems, this may not hold true for specific cancer diagnoses that create physical disfigurement, such as sarcomas that potentially require amputation, rotationplasty, etc. Certain subsets of the survivor population may be at higher risk for having negative self-beliefs due to

their experience with their disease and its treatment. Also, while cancer survivors are not reporting poor self-concept on standardized measures, which predominate in the research reviewed above, clinical perspectives and support group settings can tell a different story.

Clinicians who provide social work support to young adult cancer survivors report that survivors frequently express worries about health, identity, ability to maintain relationships, mortality, and body image, among many other concerns (Odo & Potter, 2009). In detailing their experience with young adult survivors, the authors describe that young adults can feel very isolated and different compared to their peers, and can mistrust their bodies and their health. Young adults describe feeling emotionally and physically vulnerable as they attempt to traverse the normal developmental tasks of young adulthood after surviving the very ‘not normal’ experience of cancer at a young age. In interviews with young adult survivors in their early 20’s, Enskar and Bertero (2010) noted that young adults report having negative experiences or feelings about their life directions and personal trajectories, relationships, and bodies, however, they were found to have a tendency to counter each of these negative feelings or experiences with a positive view or expectation. This theme of counteracting negative experiences with positive images and expectations was prevalent across interviews with survivors and termed a *compensated life picture*. This compensation effect is consistent with survivors’ tendency toward repressing and/or avoiding their negative feelings.

Online support groups and organizations exist for young adult survivors to interact with others like themselves. These organizations and websites feature articles,

information, entertainment, and conversational venues for survivors, and most state that the reason they were initiated was due to the very limited psychosocial support and lack of understanding of the difficulties specific to young adult survivors. Young adults discuss the challenges of moving beyond cancer, frequently mentioning the isolation, health concerns, relationship worries, and the new “normal” to which they are constantly adjusting (Livestrong Young Adult Alliance; Planet Cancer.org; Ulman Cancer Fund for Young Adults). While many standardized measures find limited psychosocial problems in young adult survivors, clinicians who work with these youth, as well as young adult survivors themselves (through online support groups and alternate venues) frequently identify many more adjustment difficulties than research would suggest. In phone communication the author had with an online support group member, a 24-year old woman described that when asked if they (cancer survivors) are alright, survivors tend to think back to the traumatizing and miserable experience of cancer treatment and compare their current ‘cured’ state to that time, which causes them to always feel like they are “okay” now compared to then. She went on to mention that if she were comparing her current state to her pre-diagnosis life, then “no, I wouldn’t say I’m doing ‘okay’... not by that standard. But my hair isn’t falling out, I don’t get surgeries every month, and I’m not at risk of dropping dead any minute, so yeah, I guess I’m okay compared to that” (Anonymous, Personal Communication, July 24, 2011). The young woman explained that she talks to other cancer survivors all the time who say that they feel like they are not able to talk to non-survivors about their issues, because other people their age do not understand what it is like to worry about whether or not they can



have children, whether or not someone will want to marry them with all their “issues”, and whether their next doctor’s visit is going to bring bad news.

Another survivor similarly explained in a phone interview that survivors can’t tell people that they are not doing alright because everyone thinks they should be doing wonderfully as they no longer have active cancer. She went on to say, “everyone gives you positive feedback when you say you’re doing great... doctors, parents, friends... they all say how brave and amazing and strong you are when you tell them everything’s good. You don’t want to let people down. Plus, you *are* doing good compared to when you had the cancer. Survivors just need to know that it’s okay to not be okay” (Anonymous, Personal Communication, July 24, 2011). Judging by such sentiments in survivor support groups and clinicians’ experiences, it would appear that young adult cancer survivors might experience more adjustment difficulties than even the literature would suggest.

Most cancer patients will experience late effects and survivorship difficulties at some time in their lives, and often such effects will not show up until years, even decades, after their treatment for cancer. Considering the likelihood of child cancer patients having long-term complications that follow them into their young adult-hood, it is clear that studies exploring quality of life in survivors are both increasingly valuable and necessary.

### **Relationships & Social Support**

In regards to social support, evidence suggests that young adult survivors’ need for support is not being met. One study found that 75% of adolescents and young adults

(AYAs) in their sample felt that they needed more support services than were available to them (Keegan, Lichtensztajn, Kato, Kent, Wu, West et al., 2012). This is particularly problematic considering that social support satisfaction and use of supportive care services have been found to directly predict quality of life in long-term survivors in general (not specific to YA survivors), with over 52% of variance explained by support factors (Lim & Zebrack, 2006). As mentioned in the previous section, while young adult survivors do not report worrying about friendships, survivors have been found to be less than half as likely as their healthy peers to have close friends and to use friends as confidants (Barerra, 2005), which is problematic as this group reports desiring more social support than they receive.

In addition to general social support and relationships, there is also concern regarding survivors' romantic relationships and dating lives; it has been noted that survivors in this age range are less likely to be married or living with a significant other than others their age (Enskar & Bertero, 2010; Langeveld, Stam, Grootenuis, & Last, 2002). Enskar and Bertero (2010) reported that young adult cancer survivors reported more difficulty in finding a romantic partner than their peers. It has been found that treatment intensity and anxiety can affect relationship satisfaction for survivors (Thompson, Marsland, Marshal, & Tersak, 2009). To compound survivors' worries and concerns about relationships, related problems such as infertility introduce more difficulty. Fertility concerns have been shown to significantly affect survivors' willingness to enter romantic relationships (Zebrack, Casillas, Norh, Adams, & Zeltzer, 2004). Survivors can sometimes feel as if they are disappointing their romantic partners;

they can have difficulty disclosing their cancer-related problems, and relationships can end due to these struggles. Sexual functioning has also been found to be a concern in young adult survivors, with 43% of survivors noting at least “a little bit of a problem” in this area. Although women were found to be twice as likely to report dysfunction, males were more likely experience significant distress over their dysfunction (Zebrack, Foley, Wittman, & Leonard, 2010). It is clear that social functioning in regards to making close friends, sharing with others, and forming and sustaining romantic relationships can be difficult for survivors, and feeling like they are not getting the social support they need appears to be a very common problem.

### **Models of Adjustment**

With advances in treatment and research, cancer is no longer primarily considered a fatal disease, but has become a chronic illness for most (Aziz, 2002). Chronic illness or disease has been well-established as a stressor and/or traumatic event that can impede psychosocial adjustment. Wallander and Varni (1998) proposed one of the most widely used theoretical frameworks for understanding patients’ adjustment to pediatric chronic illness. The disability-stress-coping model conceptualizes chronic illness as an ongoing chronic strain for the patient and their family, and elaborates that a chronic strain is characterized by persistent objective conditions that require an individual to continually readjust and adapt, which can interfere with their well-being and adequate performance of ordinary role-related activities (Wallander & Varni, 1998). The model includes both risk and resistance factors that contribute to adjustment, the main outcome. Risk factors include: (1) disease/disability parameters (e.g., diagnosis,

handicap severity, related medical problems, cognitive functioning, brain involvement), (2) functional independence, and (3) psychosocial stressors. Resistance factors that promote adaptive functioning include: (1) intrapersonal factors (e.g., temperament, competence, effectance motivation, problem-solving ability), (2) social-ecological factors (e.g., family environment, social support, family adjustment, utilitarian resources), and (3) stress processing factors (e.g., cognitive appraisal, coping strategies). These risk and resistance factors both interact and directly act on adjustment, which incorporates mental health, physical health, and social functioning, consistent with the domains of health-related quality of life. This model provides an understanding of how chronic illnesses such as cancer are stressors, and how both risk and resistance factors determine the outcome of adjustment, which is essentially quality of life. However, to better understand *survivorship* of the chronic illness of cancer and how it is related to adjustment, the Cancer Survivor Adaptation (CSA) model is appropriate (Naus, Ishler, Parrott, & Kovacs, 2009).

The CSA model is a model of cancer survivorship that is highly applicable to young adult survivors. It is comprised of three components: personal context, adaptation process, and quality of life (Naus et al., 2009). The adaptation process is the central component of the model and is ongoing and dynamic throughout survivorship. It consists of the working self's cognitive appraisal of goals, personal scripts/identity, and beliefs, and this ongoing cognitive appraisal is thought to be the mechanism of change for survivors. The adaptation process takes place within one's personal context, the first component. Personal context consists of the journey of the cancer experience itself as

well as intrapersonal and interpersonal characteristics of the survivor, which include bio-psycho-social-spiritual factors that define the individual and impact his or her cancer experience (Naus et al., 2009). Both personal context and the adaptation process lead to the quality of life outcome of adjustment. Survivors' personal context, including intra- and interpersonal characteristics, is not static and may influence their survivorship experience and adaptation over time, and both personal context and adaptation are continuously modified by changes in the quality of life outcome. The quality of life outcome is multidimensional, encompassing biological, psychological, social, and spiritual life domains that impact survivor's adjustment. These quality of life areas exist "on a continuum of positive and negative adjustment that is multifaceted across life domains and continually changing as a function of ongoing appraisals" (p. 1355). The CSA model is similar to the Wallander and Varni (1998) model in that it recognizes cancer as a chronic illness that is a stressor which interacts with a variety of factors to predict adjustment or quality of life. However, the CSA model is directly applicable to survivors as it considers the unique stressors and experience of cancer survivorship over time rather than merely disease adjustment.

### **Quality of Life**

Quality of life (QL) is a diverse, holistic construct that is quite broad; it takes into account an individual's well-being and general satisfaction with their life across a variety of domains (Wallander, Schmitt, & Koot, 2001). The term "health-related quality of life" (HRQL), often used interchangeably with QL, may be more appropriate. HRQL refers to a patient's perception of their own well-being in light of the impact of their

disease, treatment, and survivorship on the domains of physical health, mental health, and social functioning (World Health Organization, 1948; Fayers & Machin, 2000). The term HRQL is a multidimensional construct that takes into consideration an individual's functioning across life areas, and is often considered to be synonymous or similar to adjustment or well-being.

Although objective behaviors may be present that help quantify or exemplify a person's level of functioning, HRQL primarily consists of internalized subjective perceptions of personal functioning on primarily internal processes; therefore, measures of HRQL typically rely on an individual's self-reported endorsements of items meant to address physical, psychological, and social functioning. Observer or proxy reports are frequently available for most HRQL measures as well; however, such reports of internalizing problems are historically not as effective as direct patient-reported outcomes (PRO); many studies have demonstrated limited agreement between observers and patients (Achenbach, McConaughy, & Howell, 1987; Bray, Bundy, Ryan, North, & Everett, 2010; Eiser & Morse, 2001;). Therefore, it is recommended that multiple sources of information be utilized whenever possible, with patients or survivors themselves being the primary source of information.

Fayers and Machin (2000) compiled a list of reasons why it might be valuable to measure HRQL. This list answers the question of why the measurement of HRQL is important and within the realm of cancer treatment. The reasons included: (1) comparing study or trial treatments with either curative or palliative intent, (2) improving symptom relief, care, or rehabilitation, (3) facilitating communication with patients, (4) identifying

late problems of psychosocial adaptation (in survivors), and (5) medical decision-making and prognostic value (Fayers & Machin, 2000).

HRQL is a useful outcome measure based on both medical and psychosocial factors, and valuable as both a clinical and research tool. There are some excellent HRQL measures that were developed for either child or adult populations that have been used specifically for individuals with cancer, though very little has been developed for *survivor* populations specifically, and next to nothing for *young adult survivors*. To the author's knowledge, there is not a YA-specific comprehensive quality of life measure at this time. Thus, studies aiming to study quality of life as it relates to young adult cancer survivorship have experimented with a variety of creative, systematic approaches to meet this need. Some studies have adapted popular child measures for use with young adult patients, some have used "adult survivor" measures which primarily have been normed with older adults, and others have used a collection of specific domain scales that one would intuitively expect to be relevant to this age group, such as worry scales, relationship satisfaction questionnaires, or social scales. There does not currently exist a "gold standard for assessing 'quality of life' in survivors of childhood cancer" (Zebrack & Zeltzer, 2003). However, it should be noted that one very relevant measure, the Impact of Cancer- Childhood Survivors scale (IOC-CS), was developed specifically for young adults (Zebrack & Landier, 2011). While it is not a general quality of life measure per se, it does focus on many of the same areas that HRQL measures do. It is meant to assess how survivors perceive their cancer experiences as having affecting them across eight areas: life challenges, body and health, talking with parents, personal growth,

thinking and memory problems, health literacy, socializing, and financial problems.

When compared to both a common adult HRQL measure, the Medical Outcomes Study Short Form-36 (MOS SF-36), and a psychological distress measure, the Brief Symptom Inventory (BSI-18), it was found that the IOC-CS measured somewhat different factors, with a broad range of correlations across the measures (Zebrack & Landier, 2011).

Survivors who reported more negative impacts of cancer on the IOC-CS tended to report lower HRQL and higher psychological distress. The authors pointed out that, considering these findings, survivors' perceptions of cancer-related problems are particularly important to both quality of life and feelings of distress.

Examinations of general HRQL in young adult survivors have indicated that most problems are reported in the physical rather than the psychological or social domains (Langeveld et al., 2004; Maurice-Stam et al., 2009), though psychosocial problems also exist (Meeske et al., 2001, Zebrack & Landier, 2011). Certain subsets of survivors who are more at risk for compromised HRQL have been identified and include: (a) individuals with more health complaints and physical problems (lower scores on mental and physical domains); (b) individuals with PTSD symptoms; (c) survivors who have been treated with both chemotherapy and radiation; (d) survivors of brain tumors; and (e) survivors who have experienced recurrence (Eiser, C., 2009; Maurice-Stam et al., 2009; Meeske et al., 2001). Additionally, female gender and age at diagnosis were found to be positively connected both directly and indirectly to lower ratings of HRQL (Maurice-Stam, 2009), though males report more physical symptoms as evidenced by elevated Physical Component Score (PCS) of the MOS SF-36 quality of



life measure (Zebrack & Landier, 2011). Both medical and demographic factors that affect HRQL ratings were moderated by coping, social support, and course-of-life (e.g., developmental milestones, risk behavior) (Maurice-Stam, 2009). In interview research, young adult survivors have noted that experiencing problems or disruptions with school or work can impact their overall life satisfaction and adjustment, and survivors have attributed such school or work problems with symptoms or side effects of having experienced cancer (Moll, 1998; Zebrack & Zeltzer, 2003).

Although studies show that young adults do experience compromised HRQL in some areas, most studies suggest that it is a small subset of survivors who have problems, and the vast majority experience “normal” life satisfaction. We should take note that interviews with young adult survivors and anecdotal reports from clinicians hint at even more concerns than these outcome studies indicate, suggesting that further research of the construct of HRQL/QL in young adults is warranted. It may be the case that young adults do have more concerns or problems relating to life quality, but the use of common measures do not pick up on these concerns, as young adults are frequently given adapted versions of child measures or more general adult measures. Little exists in the way of targeted young adult measures of HRQL, though many health-related quality of life measures have been adapted for use with this population and used in research and practice to detect symptoms or concerns. However, knowing that an adapted child or older adult measure has the hypothesized factor structure and is clinically valid at detecting symptoms does not mean that we know that the appropriate range of content is in the measure; there may be important constructs missing that are relevant for young

adults. Child measures do not include much in the way of body image, relationships, marriage, future worries, fertility and reproductive concerns, etc. which may turn out to be important constructs to include considering other studies' findings. Additionally, it may be the case that adapted measures that are essentially identical to child or adolescent measures have items that are developmentally less appropriate. Similarly, young adults are likely to have somewhat different quality of life concerns than their older counterparts; a 20-year-old survivor would potentially be more concerned about academics, parental influence, and developing autonomy than would a 45-year-old survivor. It would be a valuable endeavor to conduct exploratory research into what factors young adults deem relevant to their life quality and functioning to determine if adapted child or adolescent measures are working fine or if standard of research and practice should turn to more targeted measures for this population and follow in the footsteps of related measures, such as the Impact of Cancer-Childhood Survivors scale previously mentioned.

### **Young Adults as a Unique Population**

Young adulthood is a difficult time of transition and change for most individuals, but for those learning to live past a diagnosis of cancer, it can be particularly challenging. Evans and Zeltzer (2006) put it quite nicely—

All adolescents face challenges as they transition from childhood to adulthood. Emotional, cognitive, and social/developmental changes in adolescence and young adulthood impact views of self, emotional state, thinking and problem-solving, and interaction with family, peers, and others during this phase of life. The adolescent diagnosed with a malignant disease must move through this developmental process

while coping with the emotional impact of the diagnosis, the therapy for cancer, and the emotional, social, and physical late effects of the disease and its treatment.

Those transitioning from adolescence to young adulthood are charged with a variety of developmental tasks, including: leaving the family home (in western cultures), developing a sense of autonomy, making career or college choices, finding companionship through friendship and romantic relationship, and often marriage and beginning a family of one's own (Beatty, 2002; Erikson, 1950). These tasks and milestones differ from those that represent younger adolescence and older adulthood. Studies with this age group of survivors have varied in their interpretation of the exact age range that captures young adulthood, with cutoffs ranging from as young as 17 and as old as 40. However, most survivorship studies characterize young adulthood as beginning sometime around estimated high school graduation age (typically 18) and going up to the late 20's or early 30's (Patenaude & Kupst, 2005; Bleyer, 2005; Bleyer et al., 2006). The charge of becoming an effective member of society who functions independently of parental guidance and monitoring can be quite daunting. This is a time when individuals must rise to the occasion of determining their own life paths and make choices about who they are and what they value. Some researchers have suggested that this a time when patients can potentially 'drop the ball' with treatment, medical adherence, and self-care (Kondryn, Edmondson, Hill, & Eden, 2010), while others have noted that patients in this period have a tendency to be overwhelmed by the flooding of choices and foreclose on their options, choosing not to explore directions but rather to revert to and rely on the opinions of others in determining direction (Madan-Swain et al., 2000; Stern et al., 1991).

Beyond young adult survivorship being a particularly challenging period of adulthood in which many new transitions, responsibilities, and risks are encountered, there seems to be a gap in both services and measures for young adult survivors. Survivors often are treated by pediatric providers until they become too old and then make the jump to adult treatment providers, with no explicit services aimed at YAs directly in order to bridge this gap. Furthermore, this tag-along approach often involves using HRQL measures developed for children and adolescents or the general adult population, not YAs specifically. This discrepancy taken together with YA's overall heightened risk for adjustment problems and posttraumatic stress symptoms highlights the need for more support and understanding of this interim age group of child cancer survivors.

### **Study Purposes & Hypotheses**

Although the majority of survivors are successful in adjusting to life after cancer, ample evidence indicates that a subset of survivors of child cancer are at risk for a host of negative outcomes, including physical, social-emotional, and cognitive challenges. These problems appear to be most prevalent for young adult survivors, indicating a need for good measurement and screening tools to monitor the psychosocial health of this potentially vulnerable population. However, young adults are often lumped into either the child or adult camps when it comes to treatment and service delivery, and non-targeted measures may not be the most accurate indicators of functioning, as noted in earlier discussion regarding the discrepancies between self-report measures of HRQL and interview data or support group climates. Such effects could be due in part to the

measures not tapping into all of the unique needs the developmental stage of young adulthood might hold for child cancer survivors (missing factors), or characteristics of young adult survivors themselves that may cause members of this population to answer over-positively on measures, or it may be that even the style or method of measurement may not be a good “fit” for this age group.

While in many ways it makes sense for young adult survivors to continue follow-up care with their pediatric team, discrepancies in research and “member” reports suggest that this specific age group may benefit from more developmentally targeted measures or methods of support and care. As these discrepancies in outcome reports occur, it becomes increasingly important for researchers and clinicians to step back and take a good look at the needs of this population in order to provide the most effective care possible. Often the best place to start with regards to understanding a population’s needs is to go directly to the source; in this case, survivors themselves. Zebrack & Zeltzer (2003) point out that qualitative study of this population is much needed by stating that reports directly from survivors themselves are the clearest expressions of survivors’ ways of thinking about and presenting their experiences and quality of life. It is clear that research that focuses on the first-hand perceptions, perspectives, and experiences of young adult survivors is in order. Such research could determine the need for measurement approaches especially targeted to YAs, particularly if we are to adequately screen for and treat adjustment problems in this most vulnerable group. This leads us to the question addressed in this study: “What *are* the unique quality of life-related concerns that young adult survivors might face?” Other studies have worked at

developing more targeted measures for young adults, and while these measures may be doing an adequate job, we are unable to truly ascertain that until we step back and identify exactly what survivors' needs and concerns are in a way that does not introduce *a priori* expectations or positivistic development techniques.

This study will employ focus group data collection methods in order to further explore what those needs and concerns might be on a first-hand, qualitative basis. It is expected that survivors will report a wider range of concerns in the focus groups than is currently evident in most of the positivistic survey studies, and results will more closely match the concerns reported in the limited interview research and mirror preliminary interviews with survivors from online young adult support venues. This expectation is based on the reasoning that the focus group approach will involve more rich discourse with peers who are also survivors, thereby providing opportunities for participants to hear about others' concerns, in effect letting them know that "it's okay to not be okay". This essentially grants permission to the survivors to express concerns or problems they might be having without fear of judgment or misunderstanding. The focus group method also allows for more in-depth probing and clarification of responses. If it is the case that more problems are endorsed in this style of measurement (focus group interviews) than are suggested in the survey literature, it would suggest that perhaps a multi-method approach in gathering psychosocial data from young adult survivors would be beneficial. Results from this study will contribute to the literature by identifying the needs and concerns of one of the most vulnerable populations of cancer survivors in a way that has yet been done. Results can contribute to ongoing measure development, as well as

increase our knowledge of challenges to adequate measurement of quality of life in young adult survivors. Most importantly, results will give young adult survivors a voice in the research and can guide improvements and developments in treatment, support, and care of this unique population.

## **CHAPTER III**

### **METHODS**

#### **Design and Methodology**

The research question of “What are the concerns or challenges associated with being a young adult survivor, as survivors themselves perceive them?” was addressed using a grounded theory study design that involved initial informal phone interviews with three young adult survivors from online support groups, as well as one informal phone interview with a support group moderator, prior to conducting four main focus groups. These initial interviews served as pilot interviews to help refine the questions to be used in the four focus groups which, together, were the primary data collection tool of this study. Focus groups are excellent tools for answering questions related to “the perceptions, feelings, and thinking of consumers about issues, products, services or opportunities” (Krueger & Casey, 2009). Focus groups involve a facilitated group discussion with a selected group of participants believed to be representative of the population of interest to the study; these group discussions are based on precisely formulated questions and probes aimed at eliciting a breadth of information on participant “perceptions on a defined area of interest” (Mactavish, Mackay, Iwasaki, & Betteridge, 2007, p. 137). The initial survivor and support group moderator interviews were conducted in order to form initial impressions that could be used to develop a thoughtful questioning route for the subsequent focus groups.

The data collected through the focus groups were analyzed using qualitative theme analysis, and grounded theory methodology specifically. Grounded theory is a



research design and analysis method which begins with purposive and theoretical sampling, constant comparative analysis, and initial coding (identifying thought units, developing initial categories), and moves to intermediate coding (including axial coding that looks at relationships among categories), selecting a core category, identifying categorical hierarchies, and achieving theoretical saturation, and is followed by advanced coding which may employ storyline techniques to integrate and present theory, and then utilizes theoretical integration to situate the grounded theory study in relation to a theoretical body of knowledge (Birks & Mills, 2011). The final product of such a study design using grounded theory is an integrated and comprehensive theory that has emerged from the data to explain a process associated with a phenomenon (Birks & Mills, 2011). The grounded theory model should adequately capture all of the coded data from the focus groups, and comprehensively explain a phenomenon.

### **Context for Study**

The context or pool for this study was a mixture of in-person and web-based young adult survivor support groups. It was believed that such groups would provide a rich pool for recruitment of survivors that met study inclusion criteria. Furthermore, the literature and initial exploration of survivor support opportunities suggested that such groups may provide a venue and outlet that fosters the sharing of personal experiences and individual perspectives, and indicated that survivors are perhaps more forthcoming about those experiences and perspectives in this type of setting compared to other locales. It was this reasoning that led the primary investigator to pursue recruitment for focus group participation through young adult support-based groups rather than hospital

patient pools or prior research databases. It was this context, in addition to preliminary reviews and inquiry, which prompted the use of focus groups as the primary data collection method of choice rather than individual interviews or another method. It stood to reason that if survivors are more likely to be forthcoming and share their personal concerns when in a group of other similar-aged survivors, then recreating that dynamic for the data collection phase through the use of focus groups would facilitate the development of a body of data that truly represented the breadth of survivor concerns. Thus, the context of young adult survivor support-based groups appeared to be a reasonable approach for this study.

### **Recruitment Procedures and Participants**

Fifteen young adult survivors of child cancer were recruited for participation in one of four focus groups that explored quality of life concerns. Criteria for inclusion in the study were such that to be eligible: a participant (1) was currently between the ages of 18 and 30 years, (2) at least two years post-active treatment for CNS cancer, leukemia, neuroblastoma, non-Hodgkins lymphoma, or primary bone cancer, (3) was originally diagnosed with cancer prior to the age of 18, and (4) was able to speak conversational levels of English (assessed informally) to participate in verbal interactions necessary for a focus group. These parameters are in line with current definitions in the literature regarding what constitutes “young adults”, “survivors”, “child cancer”, and what types of cancers are most common for this age group. Generally young adulthood is thought of as ending at some point in the mid to late 20s, however, most research that focuses on the “young adult gap” in cancer outcomes and

survivorship call attention to individuals up to age 30, perhaps because some young adult survivors are believed to be slightly delayed in meeting milestones of this developmental period. This is the rationale for this study's use of 18 to 30 years of age as the range of inclusion. Regarding the classes of cancer that were included, CNS cancers, leukemias, and neuroblastomas are the most common cancer types in young children, and non-Hodgkins lymphomas and primary bone cancers are more common for teens or adolescents (ACS, 2012), thus individuals having been diagnosed with at least one of the above were considered for participation.

This study was conducted in accordance with the human subjects research protocol approved by the Institutional Review Board at Texas A&M University. Participants were recruited with purposive sampling, as is the standard for grounded theory research, through the use of online social support websites as well as by peer nomination. Web-based social support sites such as Facebook.com, Dailystrength.com, or Supportgroups.cancercare.org that had designated online support groups for young adult cancer survivors were identified by the primary researcher, and written recruitment practices ensued. These practices consisted of the primary investigator posting a web announcement in the open, public-access areas of the support group chat room, forum, or group page, or directly "cold contacting" potentially eligible participants by electronic mail messaging. The web announcement included a general description of the project and provided basic information about participation in the study and ways to contact the primary investigator for more information about the study (Appendix A). While there are formal guidelines for web-based research, there do not exist guidelines specifically for

internet recruitment. The American Psychological Association (APA) and other professional organizations dictate that web-based participant recruitment strategies meet the same standards as print-based recruitment materials, such as flyers or newspaper advertisements. However, both the Partners Human Research Committee and Stanford University have posted suggested guidelines for such recruitment techniques, and these recommended standards were adhered to in this study (PHRC, 2010; Stanford, 2012). The “cold contacts” involved sending an electronic mail message to individuals who have open-access public profiles on social media sites targeted at cancer survivors; typically these were the same sites where the web announcement was posted. Individuals were identified using the search function on these support-based social sites, such that individuals or support groups who had public profiles were sought after based on public membership in cancer support groups or having any of the following search terms listed in their profiles: (1) cancer survivor, (2) cancer support, (3) young adult survivor, (4) surviving cancer, (5) young adult cancer support, (6) survivor support, (7) had cancer, or (8) cancer group. Searches were limited to five cities in Texas: (1) College Station, (2) Houston, (3) San Antonio, (4) Austin, and (5) Dallas. Of the profiles that were identified through the search function, only those that were designated as “public” were contacted with an email message that provided general information about the study and how to contact the primary investigator for further information about how to participate (Appendix B). Individuals whose profiles were labeled as “private” were not contacted. Potential subjects were sent the recruitment email message once, and if they did not respond they were not contacted again. Participant peer nomination was the other

method of recruitment utilized, also called the “snowball” method. Participants in the study were asked if they knew anyone else who would meet criteria for inclusion and might be interested in participating in the study. Participants who did know some such persons provided the first names and email addresses of potentially interested individuals to the primary investigator, who then contacted them with an informational recruitment email (Appendix B). The participants who nominated individuals were asked to inform those nominees that the researcher would be contacting them by email shortly.

Once a potential participant contacted the primary investigator by phone or email and expressed interest, a more in-depth explanation of the study was shared with him or her by email or phone, and the pre-screening questions regarding eligibility criteria were asked. If a participant met the eligibility criteria and he or she exhibited continued interest in participation, a phone conversation was conducted during which the informed consent was discussed with him or her (Appendix C). The informed consent document was emailed to each participant as an attachment, so that he or she could review the document prior to the scheduled focus group meeting in and have time to think about any concerns or questions they might have. All individuals who expressed interest in participating in the study were told their names would be placed on a list, and a random sample would be chosen to participate in a focus group, and that even if an individual was not drawn for focus group participation, his or her name would be entered in a drawing for a \$50 Target gift card as a thank you for his or her willingness to participate.

A list of potential participants was drafted for each of the five locations, one at a time as it was not known how many focus groups would need to be conducted up front,

and a semi-random sample of four to five individuals was drawn from each list to be contacted for participation. The sample was “semi” randomized in that most individuals had an equal chance of being chosen for participation, however, due to the shortage of males in the sample, males were immediately included in the group of selected participants contacted in an attempt to diversify the gender make-up of the group. Once the semi-randomized list was constructed, the first four individuals were contacted for participation. If one of these individuals declined participation, the next individual on the list was contacted. This method of contacting participants continued until four individuals had explicitly agreed to participate. These participant lists were constructed and focus groups took place until no new themes were emerging in the groups. Due to the sensitive nature of the subject matter, each participant was offered the option of choosing to complete a private interview in place of the focus group, though focus group participation was encouraged. All individuals contacted expressed a preference for participating in the focus group interviews. At each focus group session, written informed consent was obtained, each participant completed a brief demographic form, participated in an audio-recorded group interview led by the primary investigator lasting 1.5-2 hours, received \$25 cash as a thank you for participation, and were told that they may be contacted in the upcoming months to participate in a 5-10 minute phone follow-up “member check” interview.

Out of 24 individuals contacted, a total of 17 participants agreed to attend the focus group interviews, however, only 15 of those individuals appeared at the group sessions, which occurred in Austin (n=4), San Antonio (n=3), College Station (n=3), and

Houston (n=5). Three to five participants were scheduled to participate in each group. The typical range for focus groups is 4-8 individuals, however, when groups will potentially involve topics that are sensitive or elicit strong emotions surrounding a difficult experience, it is recommended to keep the groups smaller in order to preserve a sense of intimate conversation or privacy (Kreuger & Casey, 2009). The overall sample was 80% female, which was representative of the gender makeup of the support groups contacted, and had a mean age of 24.7 years. The ethnic breakdown was such that 73% were White (n=11), 20% were Hispanic (n=3), and 7% were Other/Biracial (n=1). Forty-seven percent (n=7) were first diagnosed in childhood prior to the age of 13, and 53% (n=8) were diagnosed in adolescence (13-18 years). The types of initial cancer diagnoses included Leukemia (n=6), Neuroblastoma (n=1), CNS cancer (n=2), primary bone cancer (n=2), and non-Hodkins Lymphoma (n=4), and one third of the participants had experienced a recurrence of their primary cancer or had experienced a secondary cancer diagnosis before the time of the study. Participants were an average of 8.5 years out of active treatment, though this ranged from 2.5 to 18 years across participants. Participant information can be seen in Table 1. It should be noted that each participant was given a pseudonym to protect confidentiality and contribute to ease of data presentation.

Table 1  
Participant Information

Participant	Gender	Age	Ethnicity	Age first diagnosed	Recurrence (Y or N)	Years In remission	Type of cancer (s)
Alice	F	25	White	9	Yes (Age 13)	9	AML
Brenda	F	27	White	4	Yes (Age 9)	18	Nblast & BT
Callie	F	19	White	12	No	5	ALL
Dave	M	23	White	16	No	4	ALL
Edgar	M	22	Hispanic	7	Yes (Age 10)	12	BT
Frida	F	29	Hispanic	8	No	18	ALL
Gabriella	F	26	White	17	No	8	NHL
Haley	F	22	White	8	Yes (Age 12)	9	ALL
Ingrid	F	21	White	15	No	4	Osteosarcoma
Janna	F	27	Hispanic	14	No	10	BT
Katie	F	26	White	16	No	10	NHL
Lina	F	30	Other: Biracial <sup>a</sup>	11	Yes (Age 24)	6	NHL
Marta	F	18	White	15	No	2.5	ALL
Nicole	F	27	White	17	No	8	NHL
Owen	M	22	White	17	No	4	Osteosarcoma

Note. ALL=Acute Lymphocytic Leukemia, AML=Acute Myeloid Leukemia, BT=Brain Tumor, Nblast=Neuroblastoma, NHL=Non-Hodgkins Lymphoma.

<sup>a</sup>Biracial ethnicities for “Lina” were Asian and Hispanic

### Researcher Positionality Statement

As the chosen method of design and analysis for this study is such that the researcher is herself a tool in the collection and analysis of the data, it is important to include a statement of researcher positionality so that I may clearly situate myself within the scope of this research endeavor. In that effort, Jones, Torres, and Arminio (2006) point out that it is imperative to be aware of any biases that I may have, and reflect on both insider and outsider perspectives, as well as researcher identity factors that I bring to the group interviews and interpretation of the data.

First, insider status includes variables that make the researcher similar to her participants, or make her an *insider* in their group. Such commonalities can be



advantageous in interview research as it promotes a joining with the interviewees, or a more close or understanding interview experience with the participants. However, it is also a type of bias, and can color how the researcher interacts with participants and interprets the data collected. In my case, my insider status is one of a young adult. As a 28-year-old woman, I am within the very age range targeted by this study, and I myself am tasked with many of the same developmental milestones of this period: completing my education, pursuing a profession that I care about, developing meaningful mentor relationships, social relationships, and romantic relationships, considering marriage and children, and planning for my future.

Second, my outsider status includes the ways in which I am fundamentally different from my participants, and makes me “other” rather than “one of us”. The most striking difference between the participants and myself is that I am not a cancer survivor. I do not know what it is like to confront my mortality so acutely and live with the constant threat of my cancer coming back. I am a relatively healthy woman who does not have to be overly concerned with my health management and self-care, at least not in the same ways that someone who has experienced such a health crisis has. I did not have years of my life, education, and development disrupted by a disease or aggressive and difficult treatments, and I do not have to live with the cognitive, emotional, or physical side effects or symptoms that many survivors experience. Such an outsider perspective means that I cannot truly understand the unique experiences of this population on a first-hand basis. Such a perspective can lead to a biased position of sympathy or guilt on the behalf of the researcher, therefore it is important to be aware of and acknowledge these

feelings, and process them outside of the group setting. In data interpretation, it is important to remember that life and people are not either struggling and sick or privileged and healthy, and each person has unique challenges, experiences, and successes.

Third, the researcher's personal and professional identity can contribute to the collection and interpretation of data. I bring to the data a personal belief that people are incredibly resilient, and even in the face of hardship can find unique and creative ways to thrive. I have worked in and continue to gain experience in hospital settings with child, adolescent, and young adult cancer patients and survivors and their families as a supportive mental health therapist and diagnostician. These experiences afford me the opportunity to witness survivors' struggles and concerns in an active and direct way, and it was this contact with survivors that made me aware of the need for such a study in the first place. Witnessing and taking part in patients' and survivors' lives and hearing the continued sentiment that survivors felt unsupported or were struggling with their quality of life instilled a desire to bring a voice to those survivors in the research and literature. Such experiences can lead to a sympathetic or "activist" bias, therefore it is important to emphasize the outcomes of the data, and let those outcomes and themes emerge only from the data and not from my preconceived beliefs or sentiments. As a researcher, my position is one of training in quantitative and empirical methods and analysis, and as such, I have an innate desire to categorize, sort, label, and make sense of processes and trajectories. It has been important for me to remain aware of these biases throughout this

study and to actively refrain from super-imposing structures, classes, or models that do not directly arise from the data.

Jones, Torres, and Arminio (2006) describe that the biases of insider and outsider perspectives can act as a checks and balances system for the researcher; in one sense I have credibility and power of access (status as a young adult, experience working with survivors), and in another sense my power is limited by not truly achieving the “one of us” status (lack of experience as a cancer survivor). This can provide a good balance of both researcher engagement and need for objectively focusing on the participants’ perspectives and experiences. Additionally, one’s personal and professional identity should not be dismissed as the researcher is considered the primary tool of qualitative analysis; however, biases should be mediated where necessary and possible.

### **Data Trustworthiness and Integrity**

Establishing both validity and reliability is particularly important in qualitative research. In the interest of maintaining the integrity of the data, a variety of methods for quality assurance were utilized (Brink, Van Der Walt, & Van Rensberg, 2005). Validity is concerned with establishing accuracy and truthfulness, and asking “Do I have an authentic portrait of what I am looking for?” Five strategies for upholding standards of validity were used. First, objectivity was attempted by developing concepts, categories, and theories from survivors’ own narratives; in other words, outcomes were emergent entirely from the data, and this emergent analysis followed the well-established method of grounded theory. Second, any responses or emotions that might arise for me were acknowledged and processed outside of the interviews through use of written memos

and sharing and examining them with my research advisor. Third, peer debriefing, in which the researcher shared conceptualization and biases with an uninvolved peer to probe for biases and concerns was conducted. Fourth, member checks were conducted with 4 participants to be sure that resulting models accurately capture survivor experiences and perspectives, and to allow the researcher to ‘test’ the results. Finally, a chain of evidence is established for each category in the resulting grounded theory model, whereby the category is fully explained and meaningful quotes are presented as evidence that the category reflects the data. This allows other researchers to make the determination of whether or not the categories and model descriptions actually arose from and capture the data. To establish reliability, a second rater coded a randomized sample of data from each transcript and this coding was compared to the primary investigator’s coding to estimate inter-rater reliability, and a full audit trail consisting of dated memos and notes was kept so that others may follow similar parameters in an attempt to reliably reproduce the results. Lastly, a word frequency analysis using qualitative software was conducted in order to loosely test the “fit” of the grounded theory model.

### **Data Collection**

Prior to the start of the primary study, the primary investigator contacted individuals thought of as being “group members” or “survivor insiders” in order to gain advice or insight that would aid in the development of thoughtful questions and probes for the focus group interviews. Three individuals from online support group sites agreed to participate in a phone conversation, and one support group leader participated in an

informal phone interview. Getting the insights and opinions of the individuals who are “in the know” for this group served as a sort of check to ensure that the questions in the focus groups were relevant to the population without being leading or too vague. This sort of pilot-style information guided the development of the first focus group questioning route script.

Once the purposive sample of participants was recruited through the use of web-based advertising, contacts, and peer nominations, the focus groups of 3-5 individuals were scheduled to take place. The four focus groups were scheduled at least three weeks apart to allow for proper planning, adjustment of questioning route as needed, and the constant comparative analysis necessary in grounded theory research. The pre-screened participants were notified of the final date, time, and location at least two days prior to the scheduled meeting, and were reminded that refreshments would be served and cash incentives would be distributed at the end of the 1.5 to 2 hour meeting. At the beginning of every focus group participants’ informed consent was obtained, and each person completed a participant demographic form (Appendix D). This was a short form that asked for the participant’s name, type of interview they agreed to participate in (individual or focus group), ethnicity, age, age of diagnosis, time in remission, type(s) of cancer and treatment received, student status, employment status, and current living arrangements. This was used for the purpose of accurately describing the sample and further understanding apparent trends in the data.

At each scheduled session, after participants completed the informed consents and demographic forms and helped themselves to refreshments, the focus group

interview commenced. The group setup consisted of a preconfigured circle of chairs with each person's chair labeled with their name on a note card. During the time that the participants were getting refreshments, completing their demographic forms, and introducing themselves to other participants, the primary investigator observed these interactions and, based on the estimated interaction level of the participants, placed their names on the chairs in a seating order deemed to elicit the most conversation. Focus group researchers have suggested that individuals who are believed to be more talkative or dominant be seated directly next to the moderator, and individuals who appear to be less talkative or shy be seating directly across from the moderator to facilitate eye contact and encouragement (Kreuger & Casey, 2009).

At the start of each focus group, the primary investigator provided a brief introduction to the process, encouraged all individuals to speak during the group, and reminded everyone that the session would be audiotaped for the purpose of later transcription. At this point, the audio-recorded interview began, and the moderator led the group discussion by asking semi-structured questions from a questioning route script that included questions related to the perceptions and experiences of the survivors across areas of their lives. These questions were formulated with the help of the piloting "member" interviews that took place during the study design phase, and were designed to spark conversation and lead to rich answers, anecdotes, and stories from the participants. The tone of each focus group interview was conversational, and the semi-structured nature of the questioning route allowed for deviation when the participants brought up new information or topics, or the discussion topics took place in a different

order. This fluidity allowed the data provided in the conversations or interviews to be determined by the participants, and the moderator merely took a role of periodically redirecting the conversation in order to keep it from wandering too far off topic. The constant-comparative and iterative nature of grounded theory research as well as the semi-structured nature of the interviews called for adjusting the questioning route in between each focus group as needed. Questions or probes that did not appear necessary or effective were discarded and any new probes that appeared to be necessary were added. The questioning route started out much longer and more structured, however, it was noted in the focus group that many of the questions or probes had a sterile feel, or seemed repetitive or not necessary and were therefore removed. The initial questioning route for the first focus group can be seen in Table 2.

Table 2  
*Initial Focus Group Questioning Route (Prior to Edits and Adjustments)*

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*Opener/Introductory—*

- 1) First, we'll go around the circle—please share your name and tell us how old you were when you found out that you had cancer.

*Transition Question—*

- 2) Are there ways that being a cancer survivor makes you different from other people your age?

*Primary Questions—*

- 3) Alright, I want you to think back to when you were in active treatment for cancer and how life was then. Compared to that time in your life, how would you say you're doing right now?
- 4) Okay, now I want you to compare your life to how you think someone your age who has never had cancer would be, compared to that person, how would you say you're doing right now?
- 5) On the notepad next to you, take a moment to list all the areas of your life that have been affected by being a cancer survivor, and then we'll share them with the group and discuss them.
- 6) All things considered what would you say is the *most* difficult or concerns you most?
- 7) What helps you or what would help you (get the things you need)?

*Probes—*

*DISCUSS/PROBE EACH AREA MENTIONED, IF CERTAIN AREAS NOT BROUGHT UP, PROMPT DISCUSSION BY USING THE FOLLOWING (This should take up the majority of the group time):*

“Tell me about...”

- People in your life
- School or work
- Independence
- Expectations for the future

Table 2 Continued

	Your health and physical functioning
	Your feelings about yourself
<i>Summary/Ending Question—</i>	
8)	To summarize, it sounds like... (give a 2-3 minute summary of researcher's interpretation of what was shared and any important points that were mentioned). How well does that capture what was said here? Can you think of anything that could be added?

---

After the first focus group and subsequent iterations, it was noted the survivors tended to talk about these issues on their own without me providing the questions, and the “think back” or “compare your life” questions were not actually used in the groups because they did not seem to “fit” the flow or dynamic of the conversation and were deemed by the moderator to be largely unnecessary. Additionally, the “Tell me about...” probes were not utilized as in the actual group sessions these prompts felt like they would be too leading, and it was important to the primary investigator that any data that emerged was actually initiated by the participants rather than imposed by the moderator. Probes such as “Are there any other areas of your life that are affected by being a cancer survivor?” were used instead. The evolution of the script was such that it was changed in between every focus group, but the essential components of the final version of the script that was actually most effective and used by the moderator can be seen in Table 3. The length was reduced, probes were removed, and overall, it was meant to be a simple set of guidelines for moving conversation forward. Additionally, a couple questions were added based on topics that came up in the group discussions. Participants mentioned things that would help to make it better or easier, and consistently made statements like “What I *should* be doing at this age” or “I’m behind where I *should* be”, thus it was



determined necessary to query exactly what participants meant by that, or what they thought it was that they should be doing. Essentially, this question identified how participants defined “normal”.

Table 3  
*Actual Focus Group Script After Edits and Adjustments*

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*Opener/Introductory—*

- 1) First, we’ll go around the circle—please share your name and tell us how old you were when you found out that you had cancer.

*Transition Question—*

- 2) Are there ways that being a cancer survivor makes you different from other people your age?

*Primary Questions—*

- 3) On the notepad next to you, take a moment to list all the areas of your life that have been affected by being a cancer survivor, and then we’ll share them with the group and discuss them.
- 4) What makes it better or easier, or what would make things better or easier for you?
- 5) What is it that you feel like you “should” be doing at this age? What do you mean when you say “normal” people?

*Probes/Prompts— (used as needed)*

- “Are there any other areas of your life that are affected by being a cancer survivor?”
- Is there anything that makes that better or worse for you?

*Summary/Ending Question—*

- 6) To summarize, it sounds like... (*give a 2-3 minute summary of researcher’s interpretation of what was shared and any important points that were mentioned*). How well does that capture what was said here? Can you think of anything that could be added?
- 

During the focus group, participants needed minimal prompting or encouragement to share. It appeared that the participants enjoyed the opportunity to engage with other survivors and exhibited enthusiasm and excellent engagement with each other. While each was slightly different, each had a good flow and group dynamic and most members were highly verbal and interactive. After the focus group sessions, participants were thanked for their participation and received their incentive envelope which contained \$25 in cash.

Shortly after the last focus group was conducted, one member of each group was randomly chosen for a brief follow-up “member check” interview. During this time the primary investigator shared the results of the analysis and interpretation of the data, including the grounded theory model, to determine if the members felt that the interpretation was an accurate portrayal of their survivor experience and adequately captured what was said in the groups. The four members who participated in these follow-up interviews were in agreement that the interpretation of the data was a fair and comprehensive portrayal of their survivor experience and fully captured what was shared in the groups. All four members were enthusiastic about and supportive of the model explanation.

### **Data Analysis**

This study employed grounded theory as the method of design, whereby the final product of which is an integrated and comprehensive theory emerging entirely from the data to explain a process associated with a phenomenon. Birks and Mills (2011) describe a modern take on grounded theory design which integrates the original suggestions of both traditional camps of grounded theorists (Glaser & Strauss, 1967; Strauss & Corbin, 1990), and this set of detailed methodological standards was used for this study. In this grounded theory method, inquiry and analysis occur through initial, intermediate, and advanced coding that are part of a constant comparative and iterative process. This means that analysis was ongoing and began as soon as the first focus group data were collected. Throughout the entire data collection and data analysis phases, a log of ongoing dated field notes and memos was kept, detailing each step that was taken. This

log of notes is helpful in maintaining researcher integrity, standard documented methods, and creating an audit trail so the analysis may be reviewed and replicated as needed. In grounded theory, data are continuously collected and analyzed until no until no new themes or concepts emerge, or the categories are 'saturated' (Kreuger, 1997). This means that once a focus group was conducted for which the resulting coded transcript data did not yield any new categories, then data collection is considered complete. This occurred after the fourth focus group in this study. NVivo 10 qualitative analysis software was used for housing the transcripts, coding, and modeling.

### **Initial Coding**

The first step in this grounded theory qualitative analysis was the verbatim transcription of the focus group audiotapes into traditional unabridged transcripts. Once transcribed, the transcript was reviewed and summarized for understanding, then initial coding took place. During the initial or "open" coding stage the first transcript was gone through line by line and thought units were identified and labeled by a few words that captured the meaning of the thought (Beyea & Nichol, 2000). The first transcript produced 502 thought units which were then organized into idea clusters or general themes. Idea clusters, or initial categories, are themes or topics that can loosely categorize statements made by participants; these themes help the researcher determine the key categories or commonalities in the data. Once initial categories were defined from the first transcript, they were placed on working codes list, which held all categories or codes that were created at each stage during analysis. The working codes list was revisited after every coding session from each transcript. At the end of the initial

coding stage, 37 loose categories were identified from the 502 thought units. Once these 37 categories were defined, the primary researcher went back through the first transcript line by line and re-coded each thought unit using only the category labels to determine if they “fit”. This type of back translating is a testing of the categories of sorts, as it is expected that if the categories are developed from a set of raw data then applying those categories to categorize that very data should be possible. This allowed for further refinement of the categories. These 37 categories collapsed and condensed into a final list of 25 categories from the first transcript (Appendix E).

### **Intermediate Coding**

After each subsequent focus group took place, the transcripts were each gone through with the working coding list that contained the 25 categories, and each thought unit was coded by those categorical labels. When a piece of data came up that did not fit under an existing category, a new category was created. The second focus group added 12 main categories (Appendix F), the third focus group added 1 main category (Appendix G), and the fourth focus group added no new categories (Appendix H). Therefore, at the end of transcription there were 38 loose categories. Upon completion of transcription and basic coding, all of the raw data units were reanalyzed under each respective category, and further explained by grouping into subcategories. These narrower subcategories were characterized in terms of evident properties and dimensions, and descriptive labels were applied. During this process, existing categories undergo further refinement and collapsing, and a hierarchical structure is defined. The end result of intermediate coding and refinement was a final list of 24 categories, most

of which contained multiple levels of subcategories (Appendix I). This traditional hierarchical mapping of the data under main categories and further subcategories is the most used qualitative approach and is expected to bring order and meaning to the abundance of raw data and lead to the identification of the central category, or phenomenon, of the grounded theory model.

### **Inter-rater Reliability**

Reliability was established in part by a measure of agreement between the primary coder and a secondary coder at the intermediate level of analysis. Inter-rater reliability was estimated through the use of NVivo 10 and Excel. First, NVivo pulled a random sample of raw data from every category from each transcript. This sample of raw data consisted of 133 thought units. The second coder, a master's level graduate student trained by the primary researcher to do intermediate level coding, coded the sample of data independently, such that each piece of raw data was categorized under a hierarchical code. After the NVivo sample of data had been coded separately by both raters, each categorical label was given a numerical code in order to obtain a Generalized Kappa Coefficient using a modified excel template (King, 2004). Reliability analysis of the coding produced a kappa of .91, which is considered excellent in coding qualitative data (Hrushka, Schwartz, Cobb St. John, Picone-Dicario, Jenkins, & Carey, 2004). After the reliability analysis, the two coders went through all discrepancies to discuss disagreements and consider any modifications necessary; Hrushka et al. (2004) describe this as the 'Reconciliation & Merge' step in qualitative coding analysis. Based on the analysis, codes and categories were deemed reliable, and were used in the final model.

### **Advanced Coding and Analysis**

Advanced analysis involved using the 24 finalized categories to lead to the final product of the study, the grounded theory model, which is the ultimate goal of all grounded theory research. It is during this stage that a full explanation of how the categories interrelated to explain a model of young adult cancer survivorship was described. The model comprehensively integrated all of the categories and subcategories. In addition, during this final stage of analysis storyline techniques were used to integrate and present the theory in a “story” of survivorship. Finally, theoretical integration was utilized to situate the grounded theory study in relation to a theoretical body of knowledge, and implications for practice and research were considered.

## **CHAPTER IV**

### **RESULTS**

The overarching aim of this study was to answer the question, “What concerns or needs do young adult survivors report as a result of having survived child cancer?”. There were 17 themes that emerged from the data to describe the ways in which young adults perceive their lives as affected by being a survivor. Themes are situated within a grounded theory model that aims to contextualize and explain the survivor experience for this sample of individuals. These 17 themes were found to fit under the “Intervening Conditions” component of the model, and will be discussed at length in that section. First, the full grounded theory model will be presented at a glance to provide a framework of understanding for the following descriptive sections. Next, each component of the model will be addressed in further detail by identifying the categories and subcategories that fit within each component and ample use of participant quotes will aid in bringing life and meaning to each category and description. Finally, a storyline technique will be utilized to paint a picture of the “story” of young adult survivorship, which was constructed solely from participant perceptions.

#### **Grounded Theory Model**

Strauss and Corbin (1990) defined what they called the “paradigm model” of grounded theory, which is considered a rigorous and comprehensive model approach to qualitative data and is comprised of six components. These components include: (1) Causal Condition, (2) Phenomenon, (3) Context, (4) Intervening Conditions, (5) Actional or Interactional Strategies, and (6) Consequences. These elements may be

positioned in a variety of orders and interrelate in many ways, and the grounded theory model may be expanded as needed to include additional elements. The basic six elements required for constructing a paradigm model of grounded theory can be seen in Figure 1.

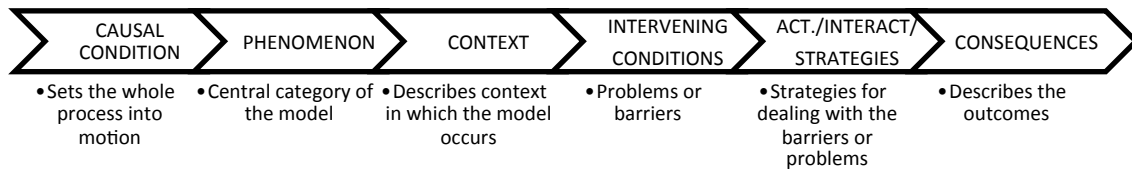
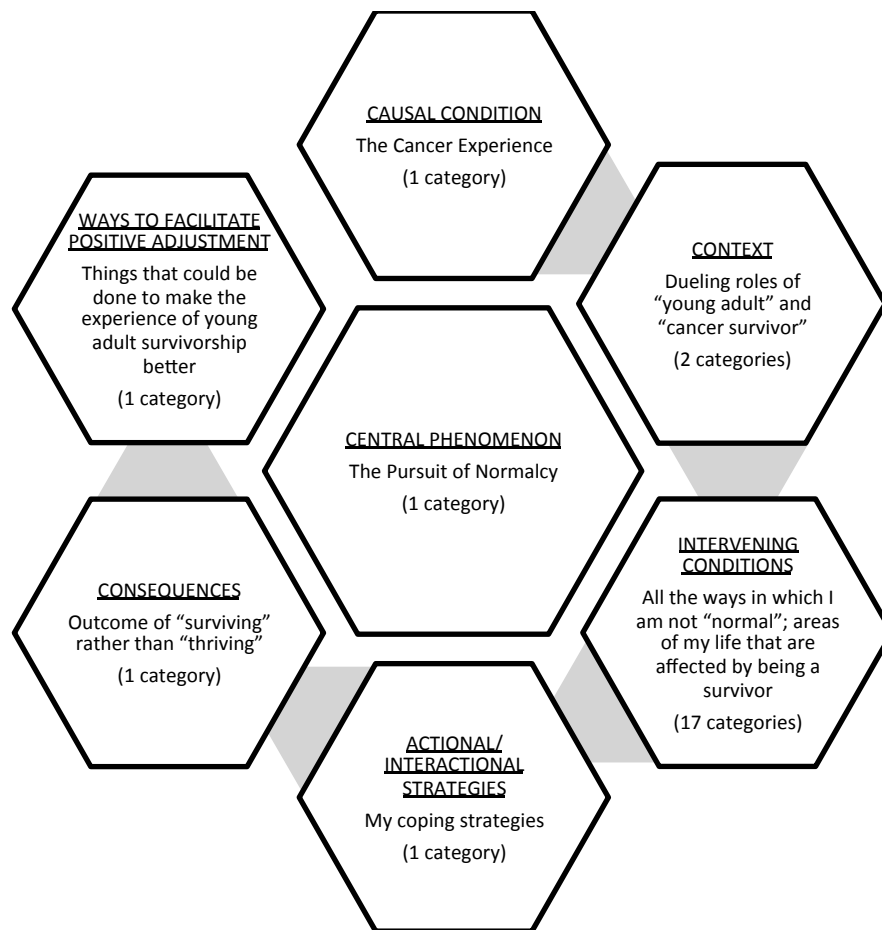


Figure 1. Basic Elements of a Grounded Theory Model.

In the case of this study, 24 categories emerged from the data and were fitted into seven components of a grounded theory model (Figure 2). The traditional grounded theory model was used, and one additional component was added, which was “ways to facilitate positive adjustment”. Overall, survivors discussed their individual experiences with cancer and how they felt that being a young adult and being a cancer survivor were sometimes dueling roles, and how many areas of their lives were affected by their survivorship. They described that there were different ways in which they coped or dealt with those concerns, what the end results were, and how the whole process or experience of survivorship could be improved.





*Figure 2.* Grounded Theory Model of Young Adult Cancer Survivorship. Describes a process of pursuing normalcy within the context of balancing roles of young adulthood and cancer survivorship in the face of intervening barriers.

A linear or narrative way of conceptualizing this model is helpful. Individuals’ personal cancer experience during childhood (causal condition) can be very difficult and may disrupt normal development or lead them to feel permanently different or abnormal, which sets into motion the constant pursuit of or quest for normalcy in their lives (phenomenon). This, however, is a struggle for individuals because they are trying to reconcile competing roles in their lives; that of a young adult who should be doing

normal things typical for his or her age group, and that of a cancer survivor, which directly disrupts or challenges the role or tasks of young adulthood (context). Specifically, survivors battle a wide range of concerns that affect their life quality and further disrupt that pursuit of normalcy (intervening conditions), which leads them to engage in a variety of strategies to deal with those concerns or problems. These strategies vary in quality and effectiveness, and can lead to the outcomes of either surviving or thriving (consequences). Unfortunately, many survivors use maladaptive or passive coping strategies that lead to an outcome or final product of a survivor who feels unsupported, abnormal, and alone in his or her journeys or feeling as though he or she is merely surviving rather than thriving. However, survivors recognize that there are many ways that more favorable outcomes could be produced. Through the focus groups ideas that would make the process of survivorship easier and outcomes better were discussed; many of these focused on adjusting the actional/interactional strategies used in order to lead to the preferred outcome of thriving versus surviving. Table 4 lists each part of the model and shows where the 24 categories fit in, and then each component is discussed in detail in the following sections.

Table 4

*List of Categories and Their Places Within the Model*

<b>Causal Condition</b>	<b>Actional/Interactional Strategies</b>
1) The cancer experience <b>Phenomenon</b>	22) Coping & strategies <b>Consequences</b>
2) The pursuit of normalcy <b>Context</b>	23) Outcomes or results <b>Ways to Facilitate Positive Adjustment</b>
3) What people my age should be doing, what is normal	24) What helps or would help to make it better for me
4) Cancer changes everything <b>Intervening conditions</b>	
5) Confusion	
6) Lack of control	
7) School issues	
8) Work & financial concerns	
9) My outlook, attitudes, & expectations	
10) Myths about survivorship	
11) Expectations of survivors, being a “good survivor”	
12) Social life & interactions	
13) Lack of organized support	
14) Romantic relationships and dating	
15) Kids and fertility	
16) Parents and independence	
17) Frustration with doctors and health care	
18) Recurrence	
19) Physical or body concerns	
20) Self esteem and self efficacy	
21) Psychological and emotional problems	

**Causal Condition**

The causal condition of a paradigm grounded theory model usually represents a set of happenings or events that influence phenomena, or describes what sets a process into motion (Strauss & Corbin, 1998). In this study the causal condition emerged as the single category of “the cancer experience”. Participants all discussed their unique cancer experiences, and experiences varied across individuals in terms of age and type of diagnosis, how they learned about their cancer, how intense treatment strategies were, how long they were in active treatment, and whether or not they experienced recurrences. Overall, participants agreed that it was the actual experience of having cancer that set into motion the whole process of coping with survivorship. At the outset

of this study it was expected that going into remission would be the causal condition; however, participants were very clear that survivorship could not be disentangled from the experience of cancer itself, and consistently connected their experience as a survivor back to the experience of being a cancer patient.

In general, participants described that getting cancer as a child or teen was a really terrible and confusing experience that changed everything about their lives and how they were treated by the people around them. It was particularly interesting to hear the participants describe the word “cancer” as being memorable and meaningful at that time; they describe it as an almost sinister thing that was embodied by a sense of wrongness, and many of them distinctly remember hearing that word for the first time.

Participants Callie and Alice discuss the word cancer:

Callie: Did your mom actually use, like, the word cancer? Because my other friends who had cancer...lots of them say their parents didn't actually say the word “cancer”.

Alice: ... No, I don't think I heard her say the word cancer at first, it was just, “you're very very sick”. I think the doctor was the one I heard say that first, the word cancer... I remember being like, ‘Oh, so that's what I have!?’ and thinking it was really bad. Like you said, I remember thinking it meant I was going to die.

Participants described that hearing the word cancer is what clued them into the severity of their illness:

Brenda: “I started hearing the word cancer a lot more... it wasn't until people really started saying that word a lot, and the way they said it I think, that made me realize I could die”.

Callie: “Right? It's funny how when they start using the word cancer you just really realize something's just flat out wrong”.

Dave also discussed hearing the word cancer: “I remember they tried to be really positive about it all but I knew it was pretty bad when they said cancer... I can relate to the whole C word thing (laughs), the word leukemia didn’t scare me so much but the word “cancer” sure as hell did.”

In addition to being scared of what the word cancer meant, participants described that they thought cancer was an old person’s disease, and how they believed it meant they were going to certainly die. Callie gave a good example of this:

When my parents told me I had cancer I thought it was like, something that only old people got, because my grandpa died of cancer, and so, so, like I thought I was going to die too. I just cried because I didn’t want to die and my parents had to keep explaining that... cancer is different for kids than it is for old people and stuff.

Individuals reported that having cancer changed the way people interacted with them; friends and family responded to them with pity or sadness, and parents took it very hard. They recalled seeing their parents crying or arguing frequently, and reported that at times they felt like the whole experience was even harder on their parents than it was on them. They remembered their parents feeling guilty or sad and allowing them to have whatever they wanted and get away with behaviors that weren’t normally acceptable.

Dave explained that “people [family members] start acting crazy around you”, and others expressed similar experiences. Brenda offered:

Everyone was always apologizing to me telling me how sad or sorry they were about ‘my cancer’... like it was some terrible disease I had, and then it started making sense that it WAS a terrible disease that I had (laughs)... And you know, my parents, and everyone just started really treating me like I was a dead girl walking. They all looked at me with such sad or sorry eyes. My parents gave in to any little thing I wanted. I

definitely used that to my advantage. You really know something's wrong when your parents are doting over you and giving in to your every want.

It was important to note that participants felt as though the age at which they had cancer contributed to how affected they were by it. They described that having cancer younger is harder to remember, but you can still have side effects from it. However, it was clear that they felt as though having it as a child or teen that was old enough to remember it was worse, because then it could not be forgotten or ignored:

Edgar: You know I bet it's almost worst having it older like that because you really know what's happening, you can almost like, forget if you're little. Because you know I barely remember the first time for me, but the second time, you know the recurrence, was like, worst man, because... it's harder to forget and move past when it's later like that.

Frida: But I would say that maybe you don't see that as much if you have cancer earlier because you're young so it's not like you have a set up identity yet or something that you remember, I think it more messes up your sense of being you when you're old enough to really know what's happening. More like, *emotionally* hard, you've got more adjusting to do, right?

Participants explained that they felt that having cancer during childhood or adolescence disrupted their development and got in the way of "being normal". For example, "normal kid" things like playing sports, engaging in extracurricular school activities, making new friends, and learning to drive all went out the window with the cancer diagnosis and prolonged periods of treatment. The survivors explained that the cancer took up their whole lives, with statements like: "...when you're in the middle of the cancer... it just takes up your whole life and doesn't leave any room for anything else" or, "[everything] changed after that...life as I knew it" and, "all of a sudden the

things that are most important to you change to just wanting to be alive and healthy. Cancer has a way of doing that.” Lina, a 30-year-old nurse who had cancer multiple times describes that the first time she got cancer she was in junior high and was trying out for cheerleading, she said “cancer was pretty much the furthest thing from my mind right then” and simply, it “totally changed my life”.

Overall, individuals in the focus groups related that the cancer experience was a major turning point in their lives, and that even after the cancer was gone (though many had recurrences), they felt forever changed by the experience. As young adult survivors, they pointed to the cancer experience itself being the catalyst that set the tone for their concerns and problems later in life. The causal condition of the cancer experience was the beginning of a constant struggle to be normal again, which is the central phenomenon of the model.

### **Central Phenomenon & Context**

The core category of a model, or central phenomenon, is the central theme around which the rest of the model pivots. It can also be understood as the purpose that drives the grounded theory paradigm. The central phenomenon of this model emerged as “the pursuit of or quest for normalcy”, which was characterized by the survivors having an utmost desire to be like other “normal” people their age, having to try very hard to achieve this, and feeling like they never quite get there. Phrases such as “I just want to be another normal person”, “you’re constantly trying to be normal but you are bouncing between two... extremes of something”, “being normal is a luxury” and, “you just want to be normal... it’s definitely a fight” were abundant in the data. Survivors felt that being

normal has been the primary struggle of their lives. A young woman named Nicole explained, “we have to work a lot harder to be normal, when that’s something that comes easily for most people” and went on to say, “when you’re already naturally normal, you don’t have to think about it, it’s not a struggle for you. But when you have something that makes you so, so *abnormal*, you realize how uh, valuable it is, to be normal.” In order to understand what Nicole and her peers mean when they say it’s so hard for them to be normal, this phenomenon must first be situated within the context of the model.

Survivors described having to balance two competing roles in their lives, that of being a young adult and all the tasks, responsibilities, and expectations that come with it, and that of being a cancer survivor, and all of the hurdles and unique needs relevant to that role. The existence of this set of dual or competing roles is the context in which the whole model operates, and can help explain why survivors find achieving normalcy so difficult. Survivors explained that these two roles are often in direct conflict with one another; and went on to describe each of the two roles that made up the context component.

First, the role of being a young adult was evident; this was described by the survivors as “what I *should* be doing at my age” and is how “normal” was defined by the participants. When describing what it meant to be a normal young adult Haley stated, “In your early 20s you’re supposed to be having friends, dating, making plans for your life and working on what you want to be when you grow up (laughs)...” Similarly, Ingrid explained that being a normal young adult meant “being able to fit in, not stand out in a bad way, be accepted by other people on the same journey through their 20s...



that sort of thing you know.” Nicole agreed with this and added, “people my age are supposed to live on their own and take care of themselves”. Janna, a woman in her late 20s, stated, “...things like marriage and starting a family, developing skills to get a good job, living independently, not needing my parents, all that stuff, is important, um, what I think of as normal”. It was evident that survivors had a clear picture of what their roles and responsibilities were as young adults, however, they felt that the hurdles of being a cancer survivor directly challenged many of the elements of being a “normal adult”

The reason that survivors felt that the role of cancer survivor dueled with that of being a normal young adult was due to the sentiment that “cancer changes everything”, which emerged as the clear second category of the “context” component. Within this category, survivors stated that having cancer changed everything for them; they conceptualized it as being taken off the “normal person track” and “set on a different path”. And on that different path, one individual describes, there are “a thousand different ways it makes me different” from normal people. The survivors describe that there are fundamental differences between themselves and “the normals”. There were many instances where survivors mentioned that being a cancer survivor meant they had to think about different things, care about different things, and were just generally on a different path than most people their ages. The following are various quote samples from the transcript that capture how different from their peers survivors feel:

Alice: It’s, I just feel like my life has had a different pattern than others and I have different things to be concerned about.

Dave: Absolutely, having cancer, especially as a teenager, or even a kid I guess, just sets you on a different path from other people. There are, just,

things you have to think about, do, care about, whatever, that are just, just different. Other people have it easier.

Callie: I bet no one else even thinks about that but us [cancer survivors]. Especially when you're young like this.

Edgar: Umm, it was just like, I definitely didn't get to be a normal teenager, or kid, or whatever. And so now I'm not a normal 22 year old, it put me on the crazy track early on, haha! I was doomed to have issues! (laughing)

Gabriella: We would be on the normal person track if we never had the cancer, maybe we would be *thriving* instead of *surviving*, you know?

Owen: Yeah, once you go through that, you're different than other people because you're umm, changed. In general, different. I'm sure that "normal people" never consider their own normalness, or if they do they probably don't think of it as a good thing, haha!

Katelyn: Just another one of those ways that being a survivor kind of makes you different from the normal population. But I agree, it gets in the way of things definitely. When you're 16 and it, you get cancer, it changes everything, makes you become a different person that you probably would have otherwise. Because you know, when you're in that stage your personality and um, who you are, is still developing, you're trying to figure it all out and what you want for your life, and uhh, cancer comes along and throws a wrench into the works, sets you in a different direction. At least, I felt that way.

Haley: No matter which ways you're different from normal people, we are still just all different, not normal.

Brenda: You're supposed to go back to being a normal kid or teenager or adult or whatever, but nothing's normal. It doesn't just snap into place like that. There are all sorts of repercussions from the cancer that make your life never like a normal person's, but you're supposed to act like a normal person.

It was very clear from the focus groups that survivors feel as though they are fighting a losing battle at times; they are doggedly pursuing normalcy within the context of trying to navigate two competing worlds or roles— young adult versus

cancer survivor. Figure 3 details the phenomenon and context components of the grounded theory model and the categories and characteristics within them.

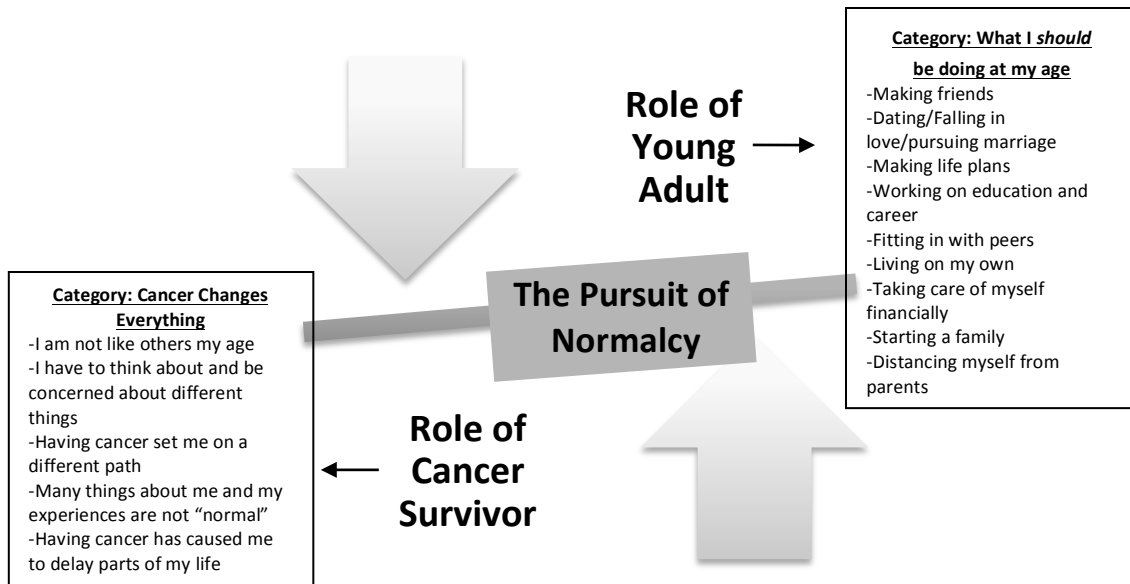


Figure 3. Illustration of the Competing Roles of the Context of Survivorship and how the Phenomenon is Affected.

The best way to characterize how the phenomenon is operating within the context of this model is: trying to be normal when I am fundamentally different. Survivors expressed that while they want to be just another normal young adult, there is no way do that after going through such a life changing experience. One survivor, Gabriella, a woman in her mid-twenties who had cancer in her teens, likened cancer to a forest fire:

Yeah, it's like a forest fire kind of, it leaves nothing untouched. Leaves everything just scrambling to survive. But you know, people say that forest fires are good for the forest though, but I say, ask the animals if they feel that way (laughing). Maybe it's a bad metaphor, but, so yeah, I

guess after cancer you can have this new appreciation for life right, sure, just like the trees grow back brighter and all bigger after a forest fire, but all of the animals, or houses, or whatever that were there before are destroyed now, like those are all the pieces of your life, and the things that survive kinda have to figure out a new way to live. Like, you're surviving instead of thriving. That's it, that's what I was trying to say.... And to take it back to your question of if non-survivors, normal people, have these same problems... sure other people could have things that happen that like, change their lives, but cancer is one of those things, like a forest fire, that you can't really go through without it for sure changing you down to your bones.

Another survivor, Edgar, mentioned that it was like coming back from war, that it makes you different from the normal population and it's something you can't really share with them. Gabriella agreed and added, "Like he said, after you come back from war I guess you're just a different person, you have had different experiences than other people". It is evident that survivors feel like the pursuit of normalcy is a difficult task; in some ways they are similar to other young adults, but in many ways they are fundamentally changed by their status as a cancer survivor. Specifically, the survivors detailed 17 ways in which they felt changed, or different than their peers, which are described in the following section.

### **Intervening Conditions**

During the focus group interviews, survivors spent most of the time discussing exactly why or how they were different from the normal population and indicated a variety of problem areas or concerns in their lives. As can be seen in Table 4, the bulk of the data or themes that emerged were in this section of the model; 17 of the 24 categories. These 17 categories are the areas or ways that survivors feel they are different from their peers, or areas of their lives in which they indicate concerns or

problems. This component of the model can be seen as a sort of problem identification stage and these identified problem areas comprise the answers to the original research question of this study: What are the unique problems and concerns of young adult survivors of child cancer, or, how do these individuals perceive their lives as being affected by their status as a survivor? Each perceived problem area is identified by the subsequent subheadings in this section; each category is discussed in detail and any subcategories or properties of the themes are explained.

**Confusion.** Focus group participants discussed that much confusion comes with being a young adult survivor of child cancer. The intervening condition of confusion was characterized by three different subcategories, depicted in Table 5.

Table 5  
*Category of “Confusion”, Subcategories, and Explanations*

	Being a survivor versus a patient	<ul style="list-style-type: none"> <li>• What does the word survivor really mean, how am I different as a survivor</li> <li>• I don’t feel differently than I did as a patient; moving from patient to survivor is not clearly delineated for me</li> <li>• I still have the same worries and fears, but I am supposed to behave differently</li> <li>• There is no roadmap for how to be a survivor</li> </ul>
Confusion	Am I “okay” or “alright”	<ul style="list-style-type: none"> <li>• The words “okay” and “alright” are vague and confusing</li> <li>• Being a survivor skews the meanings of these words for me</li> <li>• I have to think about “compared to what?” when I try to determine if I’m okay or not</li> <li>• The real answer is always both yes and no</li> </ul>
	How to take care of myself in the best ways	<ul style="list-style-type: none"> <li>• It is important for me as a survivor to take good care of my health</li> <li>• Information available about self-care and disease prevention is contradictory</li> <li>• Feel like I am floating in a sea of misinformation</li> <li>• I feel like I am not doing the right things for my health because I can’t find answers or advice</li> </ul>

First, survivors described the process of becoming a survivor rather than a patient as highly confusing. Specifically, they found themselves questioning what a survivor even was and what their role was now that they were called “survivor” instead of “patient”. Many of them described that this was difficult because even though the doctor said they were now in remission, they did not feel differently and still had many of the same feelings, thoughts, and fears; there was no line to cross or flashing light to signal that “now you’re a survivor, and that’s different”, and so they did not know how to adjust accordingly. Brenda mentioned, “It’s almost harder being a survivor than a patient” because there is not a roadmap for how to be a survivor, or an explanation for what a survivor means. She goes on to have the following discussion with Alice, Dave, and Callie:

Brenda: Umm, being a survivor, yes well, I don’t know if I mean that it’s harder really, because I’ll definitely take this over the other option, ya know? But being a survivor, that’s everyone’s goal, that’s the end goal, that’s where every cancer patient is trying to get, but it has all of its own problems too...

Alice: Not the least of which is what even *is* a survivor? I didn’t really know when I moved into survivor territory.

Brenda: Yeah, true, when are you a survivor and not a patient anymore...

Callie: Yeah, it’s not like you get to a finish line or mountain top or something and you’re like ‘okay, now I’m here’, survivor land...

Dave: It’s definitely not that clear cut, survivor land, so who knows...

Brenda: Yeah, so everyone says the cancer’s gone one day, but you still feel the same way, the same worry and dread, the same doctor’s visits to be sure it hasn’t come back, but all of a sudden they say you’re cured and nothing you feel, nothing inside you really changes. Yeah, I guess slowly people stop poking and prodding you, stop asking you how you’re

feeling, and you're supposed to go back to being a normal kid or teenager or adult or whatever, but nothing's normal.

Second, survivors described feeling confused about being "okay"; they explained that it's hard to know what the term "okay" even means, and that this is a source of stress because it is a question that they have grown to expect on a constant basis as a survivor. They described feeling as though they couldn't accurately answer the question "are you okay" or "are you alright", because being a survivor skews the meaning of words like "okay" or "alright". The participants stated that they always find themselves wanting to ask, "Okay compared to what?" They explained that once a person is a cancer survivor, one's point of reference for judging how he or she is doing is muddled, and at any given moment the answer to that question is probably both yes and no, depending on what "okay" really means. When they compare how they are now to how they were when they were in the active stages of cancer, then they feel like the answer is yes. However, if they think about how they are doing now compared to how life would be if they never had cancer, then the answer is usually no, I'm not okay; it all depends on the frame of reference for the question. The following is a sample of a conversation between two college students, Ingrid, and Haley:

Ingrid: I want to interject and say that it's not just, you don't have to be okay or not okay. It's never like that, at least for me. Usually it's both. I'm okay, but I'm not okay. Like, I'm not dying, I got this awesome prosthesis that lets me be cancer free, I'm in college and learning how to do what I want and all, so yeah, I'm okay. But at any given moment I'm probably not okay too. Something is probably really hard for me, or some area is umm, needing tackling, so yeah, it's not really a yes or no thing, like you're okay or you're not. You're both.

Haley: Yeah, and that just makes it more confusing probably, because how do you every really answer people when they ask you things like

that, I mean, I know how you DO answer them, you just say, yeah I'm fine, but I guess the *real* answer is almost always 'yes and no', then.

Edgar and Gabriella had a similar conversation about how the confusion about how to judge whether or not they are “okay” or “alright”:

Edgar: Compared to my buddies who still have cancer or freaking died from it I'm doing pretty well. And so, you just think back to when you had the cancer and say, hell, compared to that, I'm doing okay.

Gabriella: Yeah, that, and, like he said, you kinda don't know if you're doing well or not, because you think back to having cancer, and you're like, 'okay, I'm okay here, it's gone so I have no reason to be having problems. I'm not dying'. It is, it's like, that's the test, am I dying? Vomiting everywhere? No, then I'm okay! I don't deserve to be complaining.

Third, individuals expressed feeling confused about the best ways to take care of themselves. They explained their frustration at all of the confusing, contradictory, and misunderstood information available for self-care. The participants explained that as survivors, they know they should put a lot of focus on taking the best care of their own health in order to reduce their chances of future recurrence or of having any other problems, however, they expressed feeling as though the information that exists about is very convoluted, contradictory, and simply not clear. Callie described it as, “It's like we're just floating in this sea of confusion, ignorance, or misinformation... Thank you Google! But we, I guess it would be nice if... someone would throw a lifesaver and just give us the facts.” Similarly, Dave explained:

Nobody has the right answer of exactly what to do and what not to do, so how do you ever know if you're doing the right things? No one is telling you the right things. Diet and exercise, no... prayer, no meditation, no this herbal supplement, no... and on and on. During my check up when the doctor asks if I've been taking care of myself I just really want to say... I don't know, maybe- maybe not, who knows. You tell me.



Gabriella described the confusion in a similar fashion, and expressed that not knowing how to best take care of one's self can cause survivors a lot of distress and worry:

Yeah, that's a big one. Once you've had it [cancer], you know you can have it again, so you're always worried about your health, like what you're doing wrong and what you're doing right, and whatever, because you know the cancer can come back and you want to prevent that. But it's not like there's any sure fire way to do that because there's no clear answers on what we should be doing, so, so it's just a lot to, a whole lot for us to worry about.

It was evident that being a cancer survivor comes with a lot of confusion and misinformation, and participants feel overwhelmed at the daunting task of having to make sense of it. Confusion about (1) being a survivor versus being a patient, (2) whether or not they are “okay” or “alright” and, (3) how to best take care of themselves was a frequent source of stress for survivors. They felt as though they are navigating the road of survivorship with no roadmap and no clear point of reference for judging their progress. These feelings of confusion and the resulting frustrations were evident across many of the intervening conditions of the model.

**Lack of control.** Survivors expressed that another way their lives have been affected by their survivorship is the persistent sense of not having control. This was characterized by: (1) feeling helpless or powerless in regards to their lives in general after cancer, and (2) feeling like it is hard to know which parts of their lives they should try to control and which parts to just accept. One participant, Katelyn, said simply, “You have no control over your life”, and Gabriella questioned, “What else am I not able to control about myself?” because she could not control how her body responded when she had cancer. Participants expressed that having cancer created all the right ingredients for

feeling helpless later in life; Alice stated:

Like he said, all those opportunities to feel useless or helpless [during cancer] probably lead to a lot of these feelings later, like we're talking about having now, you know? ... we sort of learn how to feel, like helpless in a lot of areas, we know we don't have control of a lot of areas of our lives that other people think they have control of, but we know better.

Lina, a 30 year old survivor who had experienced multiple recurrences, shared the sentiment and stated, "...there's nothing you can do, things like that are kind of out of your control, and it can make you feel totally helpless. It's a terrible feeling to know that something sinister is right around the corner at any given moment [cancer]... and there's nothing you can do to stop it."

Participants expressed that due to having a period of their lives where they had no control over things like their bodies, treatments, plans, and even future planning, they are unsure as survivors which parts of their lives they can control now. They mentioned that even when they try to control some things like how they take care of themselves it is just a false sense of control because they cannot prevent bad things from happening again. Alice describes that even if she does all of the "right" things, "nothing I do can truly prevent bad things happening. So no matter what, it's a false sense of control".

Brenda agreed with her and added, "It's definitely a false sense of control, but you have to hang on to the things you can control, even you can't really fully control them".

Participants brought up the idea of the serenity prayer that is associated with Alcoholics Anonymous; this prayer focuses on having the courage to work on things that can be changed, the serenity to accept the things that cannot be changed, and the wisdom to know the difference. Some of the participants mentioned that this ability to distinguish

between what is or is not in one's control is particularly important and valuable for survivors; however, it is also particularly difficult for survivors. Dave explained:

Well that right there is probably one of the biggest sources of stress throughout this whole thing, this whole cancer thing. Think about it, one of the worst things is we're told we have cancer, and we have to do these terrible treatments but there's not a lot we can do ourselves to fix the problem, and then even when the cancer's gone, you just, to know that your body is flawed and can fail you at any time, and there's nothing you can do about it? So if there's really nothing we can do about it do we just throw our hands up and say screw it, whatever happens, happens? Well, maybe, but I guess we can have some control over how we take care of ourselves to make our risks less or something, right? But no, because nobody has the right answer of exactly what to do and what not to do, so how do you ever know if you're doing the right things? That whole wisdom to know the difference thing, it's hard as hell to know the difference when no one is telling you the right things. What's in my power to change and what isn't?

It was evident that survivors had some trouble with feeling as though they do not really have control in their lives, additionally they expressed not really knowing what things were in the realm of their control or not and how to make that determination. While most of the participants described this as very stressful, some individuals felt as though there could be freedom in knowing that one's life is not within his or her control, and described that believing things were fated or determined by a higher power could, in effect, pardon individuals from fighting to control uncontrollable forces in their lives, and instead allow them to focus on the things that are well within grasp. One young woman, Alice, stated:

Yeah, that's terrible and it's really frustrating and can make you feel defeated, but there's also, I don't know, a kind of freedom in that right? ...when you realize there are parts of your life that are out of control, say in god's hands, then it, umm, frees you up I guess, to focus on the things you can control.

These sentiments indicated that the survivors as a whole felt frustrated and helpless and felt like they were not in control of their lives or what happened to them, with a mood of futility accompanying the survivors' conversations about control, however, it was evident that some survivors coped with that sense of futility by embracing that there was a higher power with a plan for their lives.

**School issues.** Another theme that emerged from the group interviews with the young adult survivors was the category of school issues. Participants discussed a variety of ways that the area of school or education was problematic for them; five different types of problems, or subcategories, were noted: (1) feeling behind or having a late start, (2) dropping out or not going to school, (3) not liking school or feeling like it takes too long, (4) cognitive or learning late effects make school hard, and (5) feeling like I'm not doing what I really want school-wise. The category of school issues is illustrated in Table 6 below.

Table 6  
*Category of “School Issues”, Subcategories, and Explanations*

	Late start or feeling behind my peers	<ul style="list-style-type: none"> <li>• I feel like I got a late start when it comes to my education</li> <li>• Cancer or treatment delayed my plans</li> <li>• I pushed school back because I was unsure of what I wanted or had doubts about school</li> </ul>
	Dropped out or didn't go to school	<ul style="list-style-type: none"> <li>• Having cancer changed my priorities and I decided school wasn't for me</li> <li>• I didn't go to school even though I wanted to because I was unsure of myself</li> <li>• I dropped out of high school or didn't continue my education even though I wanted to</li> </ul>
School Issues	Not liking, or takes too long, or too inconvenient for me	<ul style="list-style-type: none"> <li>• School takes too long for me</li> <li>• I don't like school</li> <li>• Going to school would be inconvenient or difficult for (e.g. too far from parents)</li> </ul>
	Cognitive or learning problems	<ul style="list-style-type: none"> <li>• Late effects from my cancer treatment make school difficult</li> <li>• Learning disabilities</li> <li>• I need school accommodations to be successful</li> <li>• Things like memory and attention are problematic for me</li> </ul>
	Not doing what I really want	<ul style="list-style-type: none"> <li>• I'm not pursuing the level of degree I want</li> <li>• I feel like I am “settling” or compromising my goals</li> <li>• I made my education choices based on how easy or hard the program or work would be</li> </ul>

The first difficulty participants discussed in relation to school issues was feeling like they had a late start or were behind their peers. Many of the participants who attended college had delayed it by a few years either purposefully because they did not feel ready or had other concerns, or out of necessity because cancer or treatment delayed their educational pursuits. Alice, a 25-year-old, described starting school later than she should have and expressed regret; “I could have already had my bachelor’s degree right

now if I would have done things the right way". Gabriella described starting late because at first the cancer delayed going to college, but then she continued to delay it, she stated:

So you... feel like you have a good reason not to go to school at first, but then, I, I don't have a good reason why I didn't get over it and go later other than I just didn't believe I could really do it mostly. So I've really delayed it, and I don't really have a good reason anymore.

Janna had a similar experience; she described that the cancer caused her to delay school at first, but that she continued to delay it after cancer as well:

Yeah, well, for me I started later than I think I would have otherwise. So yeah, school was affected because I delayed it. Well, first the treatment delayed it, and then I felt kind of lost like I didn't know what I wanted to do now that I realized I was okay and was going to, umm, live. It took me a while to switch back to having 'normal people' priorities and uh, standards, for myself, even after I was physically okay. And then even when I thought I knew what I wanted to do, I felt like, I kind of doubted myself.... Especially with starting a little older than other people, like I wouldn't fit in or whatever.

Quite a few of the participants made comments about delaying school for a variety of reasons. The following are samples of quotes from different participants that describe school being delayed:

Nicole: I had uh, the cancer when I should have been applying and going to college, so it got in the way of that. I just umm, was really delayed in that way.

Marta: I umm, am embarrassed now because all of you are talking about college, and I haven't even applied yet. Even though I keep saying that I will and I want to.

Owen: Yeah, I know it sucks to feel like you're behind. I stayed out for a couple years too. Because the cancer. So I could be finishing up right now, but I'm uh, in the middle.

Katelyn: It's embarrassing to say you're 26 and still trying to get your bachelor's degree.... It makes me feel behind other people my age.

Lina: I ended up taking longer to do school too, because umm, the recurrence. The cancer got in the way and I had to take some time off to get better again. And then jumped back into it, so I actually just finished 2 years ago, which is later than I should have.

Ingrid: I did feel like I got a little later start because I got my amputation when I was 18 right as I was graduating high school. I had to go to summer school to make up stuff and still graduate, and then I spent that year kind of adjusting to my prosthetic and doing therapy and stuff. I was just a year late, but I, umm, felt really nervous about starting and what it would be like with this (indicated leg). But I was excited too, to get back to trying to be on a normal track and catch up to other people my age, so it was worth it. Even though it was really... uncomfortable sometimes.

The next area that emerged as part of the category of school issues was dropping out or not going to school. Some participants described dropping out of either high school or college, and some shared that they did not pursue going to college or continuing their education past high school, even though they believed they should have or wanted to. This may be affected by how participants thought of or experienced school; under one subcategory participants described not really liking school or feeling as though school takes too long or thought it was too long to be away from their parents, and under another subcategory some reported that cognitive or late effects from cancer made school difficult for them. The following are some of the participant quotes that described not going to school due to thinking it would take too long, be inconvenient, take them away from home, or just not liking it:

Alice: To be honest, I didn't move away to go to college because I didn't want to be away from my parents in case something happened, like health-wise.

Callie: I know exactly what you mean, I didn't start college this past fall and I should have. I should have done something I guess, but I don't really know if I want to spend like 5 years of my life doing more school, school was hard enough as it is, and that's a long time.

Dave: I think I should have gone to trade school or college or something but it just feels like a lot of work when you're already not that good at school stuff.

Gabriella: Oh yeah, it was really hard, especially bad because I never ended up going back [to college]. I just didn't... because I was going through a lot.

Frida: But here I am, who am I to talk, I never went to no college, I thought about it... but then I had my first baby and it would have been, like really hard. I mean I didn't even finish high school.

Owen: Sucks. I hate school.

Furthermore, many of the participants discussed experiencing certain cognitive problems or late effects with learning related to cancer and the treatment experience, which makes educational activities or going to school difficult or stressful for them.

Katelyn stated:

Because I umm, I feel like having cancer has been, umm, it has made school harder for me. I've been working on my bachelors off and on for a long time. It's just, hard for me. I didn't have so many problems with school before cancer. I was a good student, and now, uh, it's just tougher for me to get things right or stay on track.... school was harder for me, um IS harder for me, and so I have to do it in chunks I feel.

Edgar explained that he is attending school for graphic design, and talked about how difficult it is having cognitive effects from his cancer treatment:

I'm not going to lie, it's okay but it's not easy. But I think that's just me yo, because I had the brain tumors and surgeries, and it's like really hard



for me to remember stuff. Or pay attention or whatever. I've had to take classes over, like and that sucks, but it's still worth it. [Cancer] changes things about you, like my bad memory. I think that if you have cancer that affects like your brain or knowledge or whatever, then it might be worse some times when you're younger and in school because it's, it's umm, hard for you to do what the other kids are doing. Like, uhh, if you're not in school you don't realize the problems you have, like with learning, as much. So it's not that big a deal, but being in school it sucks a lot more.

He went on to say, "I already know I can't trust my mind. When I can't remember something that I just read or simple facts, I feel like an idiot and I don't want to try anymore if I know that I'm already doomed to screw something up." Janna and Haley discussed having learning effects that require school accommodations:

Janna: I kind of doubted myself because I thought I was going to have all of these brain problems and it would just be, really hard, or I would embarrass myself. It's been okay, I mean, I'm really really glad I'm doing it. But yeah, it has been a little hard. I get accommodations in my classes, like sometimes my profs let me bring notecards because my rote memory can be bad, or just little things like that. But to get that stuff, I have to share with them my issues, and have a disability report and all, and that sucks, because I don't really feel disabled.

Haley: Yeah... I've always had, um, well they call it learning disabilities, but I'm smart and everything and have always made good grades, but some things are tougher for me, and so I got accommodations in junior high and high school, and it would be pretty cool if I got those things in college too, but I didn't even know you could.

In addition to many of the individuals mentioning they had various problems associated with learning, feeling behind, not continuing their education, or not liking school, some of the individuals who had continued their education beyond high school expressed feeling as though they compromised or settled, or that they are not doing what they really want educationally. Some examples of this included individuals not getting the level degree they wanted, like getting their GED instead of high school diploma, or

an associate's in place of a bachelor's degree, because the degree path they desired seemed too difficult.

Overall, participants expressed a variety of concerns related to school and education, and these contributed to negative feelings about school, doubting their learning abilities, needing additional school supports, or choosing not to pursue their educational aspirations. Many of the same concerns that individuals mentioned about school issues were brought up in relation to the areas of work and career as well, which is the next intervening condition or category discussed.

**Work & financial concerns.** Another main theme that consistently came up in the focus group interviews was that of work or financial concerns. Participants expressed extensive worry about difficulties related to the pursuit of a stable career. While this is a concern for many young adults, group participants detailed feeling as though it is much more difficult as a cancer survivor. Individuals indicated four main areas of work-related concerns, or subcategories: (1) getting a job, (2) insurability, (3) financial worries and, (4) feeling like they are not doing what they really want work-wise. Table 7 describes the category and subcategories of work and financial concerns.

Table 7  
*Category of “Work & Financial Concerns”, Subcategories, and Explanations*

Work & Financial Concerns	Getting a job	<ul style="list-style-type: none"> <li>• I worry that I won't be able to get hired</li> <li>• I question whether I will be a good candidate for a job because of my health history</li> <li>• I am concerned that I won't be accepted in the work environment due to my differences as a survivor</li> </ul>
	Not doing what I really want	<ul style="list-style-type: none"> <li>• I did not pursue the career path I most wanted</li> <li>• I feel like I settled on a job rather than a career</li> <li>• I took the work options that seemed to be easy or available to me</li> </ul>
	Insurability	<ul style="list-style-type: none"> <li>• I have to care more about quality health insurance than others my age</li> <li>• I worry that I will have problems getting insured due to my health history</li> <li>• Insurance is highly expensive for me</li> </ul>
	Financial worries	<ul style="list-style-type: none"> <li>• I have to think more about my financial security than my peers</li> <li>• Potential cancer recurrence or health problems are very expensive and require a lot of money</li> <li>• I have to prepare financially for bad things happening</li> </ul>

The first subcategory identified under the category of work concerns was getting a job, or getting hired; participants expressed concern that they would have more difficulty getting hired at a job due to their status as a cancer survivor. The survivors explained that they worried that potential employers would not consider them good candidates for a job considering their previous health problems, or worried that perhaps they would not be accepted in the employment environment. They described that getting a good job is a big concern for them; the following quotes are samples from the participants that describe this concern:

Janna: I know it's going to be hard, hard to get a job. I don't know if I'll have to tell them about my cancer since it's been a long time since then, but you, it's just something that makes the way I think about my career path different. And um, with being a little older than other people who might be graduating because I took awhile to get here, will that, uh, make me less desirable than someone else for a job? Just have to think of what's stacked against you.

Ingrid: I told you guys I'm going for education, but will they want to hire a teacher with a visible problem like this? And... will they accept me, and whatever. You just have to think about that sort of thing.

Haley: And just also, am I even a good candidate, will anyone want to employ me, that sort of thing.

Nicole: It's been tough trying to find and keep a job without having REALLY gone to uh, college or whatever.

Lina: As a cancer survivor who is susceptible to getting it again, are you the kind of person people want to hire, or will they be worried about your health.

In addition to worrying about their employability, quite a few of the participants in the focus groups discussed feeling as though they compromised in the area of work and career. Similar to the comments some individuals made about choosing a school or education path that was easier, some individuals described pursuing a career path that was easier or more doable rather than what they really wanted to do. One young man characterized it as just working or having a job versus having a career or profession. They used phrases like "so I just got a job and worked instead" of doing what I really wanted, or "it just makes more sense to work for my dad", or "I worked instead, but not really doing what I want to do". This sort of comment was prevalent in the conversations about work and career, indicating a participant pattern of settling or just accepting what seemed available or easy. Marta, an 18-year old- survivor, provided a good example of

this: “It just seems easier to work for my uncle. I’m uh, a receptionist at his car dealership. It just uh, I don’t know, was available so I just went that direction and I wish I would have tried harder or thought more about what I really wanted.”

Not only did participants feel distressed over their job prospects and career choices, but they also noted insurability as a big worry. They expressed that as a cancer survivor, having quality insurance from a job is a must, however, because of their status as a survivor insurance can be difficult to obtain. Edgar stated, “you’ve gotta have good insurance when you get this kinda sick”, in regards to the potential of having a cancer recurrence. Haley agreed and added, “Insurance stuff is a really big worry for me.... And like, will I be able to find a job that will give me good insurance in case I get sick again, will I even qualify because I’ve had such a bad illness in the past.” This sentiment was shared by other participants; Janna explained that survivors always have to think about insurance, and even if one does all the right things he or she might still have problems securing a good insurance plan: “...Even if I get this degree and I’m out there applying and stuff, it’s scary to think that, like, will I have good insurance in case this happens again, and, will the insurance even take me, am I a liability to companies, you know.” Some participants fretted over how expensive insurance was as a cancer survivor. Gabriella remarked “I just had to get off my parents’ insurance and get on my own, and you have to pay soooo much when you were sick before.” Ingrid had a similar experience: “Since I’ve had trouble finding work, I have private health insurance and my parents have to help me pay for it because it’s so so, so expensive. But it’s not an option for me not to have insurance because if I get cancer again without insurance, I’m screwed.” It was

very clear that insurability was one of the most important subcategories under work concerns. The participants felt that it was another thing they had to think about differently than other adults their age; Lina stated, “Health insurance? Really, what other young adult is thinking about that?”

Survivors’ worries about finances extended beyond just the expense of insurance to include their general financial future.. Many of the participants explained that they have to be more concerned about being financially secured than their same-age peers because of the likelihood of having health problems in the future. A young woman named Haley stated, “I need a good job also to save money and be able to afford it if something bad happens and like, I get sick again, because my parents can’t always be there to help, and umm, it’s a big financial burden. I have to think about how to handle that stuff myself.” Frida commented on the expense of health costs, “God, yeah, just like an ambulance ride is crazy expensive, no matter what the problem is, so you can just imagine what like, chemo or surgery or stuff must cost. Ughhh, I don’t even wanna know.” Nicole agreed and added, “Cancer is a huge financial um, overload, just uh, would totally wreck your life, as if it doesn’t already, but um, would bankrupt you.” The participants felt like “normal” young adults did not have to worry as much about this sort of thing; Gabriella mentioned, “I don’t think that people who haven’t had a big illness or medical problem know what that feels like, to have, to kind of be buried under the expense of it.”

Overall, the category of work was a big concern for participants. Many felt that they would have a difficult time finding a job or getting hired, ended up settling for a job

that was not exactly what they wanted, and admitted to experiencing many worries over financial concerns and insurability. The survivors felt that they experienced these problems more so than the general young adult population, and had to devote more time and energy to work and financial concerns. It was clear in the groups that while all survivors endorsed work or financial worries, more concerns appeared to be reported by young adults on the later end of the age spectrum, likely because these individuals were somewhat less dependent on parental support than the younger participants.

**My outlook & attitudes.** Participants in the focus groups frequently discussed how their overall outlooks, attitudes, or expectations about life were different than those of their peers; this theme emerged as a distinct area that survivors felt had been affected by being a cancer survivor. Five subcategories were identified: (1) constant sense of danger or uncertainty, (2) maturity level, (3) expectations or knowledge, (4) different priorities and (5) mortality and death. Table 8 lists the subcategories and explanations that describe the category of outlook and attitudes.

Table 8  
*Category of “Outlook & Attitudes”, Subcategories, and Explanations*

My Outlook and Attitudes	Constant sense of danger or uncertainty	<ul style="list-style-type: none"> <li>• I persistently feel unsafe or in danger because my cancer could come back</li> <li>• I have to live with a constant sense of uncertainty in my life</li> </ul>
	Maturity level is different than that of my peers	<ul style="list-style-type: none"> <li>• I feel “over mature” compared to others, but behind in some ways</li> <li>• I don’t stress over the little problems in life</li> <li>• Being “ahead” of my peers can make it hard to relate to others</li> </ul>
	Different expectations and knowledge	<ul style="list-style-type: none"> <li>• I have more knowledge of life than others</li> <li>• I expect bad things to happen more than others</li> <li>• I have to think about things differently than my peers</li> <li>• I am more realistic/less naïve than others</li> </ul>
	Different priorities	<ul style="list-style-type: none"> <li>• Having cancer changed my priorities or what I think of as important in life</li> <li>• The things I have to prioritize are not things that normal young adults are concerned with at this age</li> </ul>
	Mortality and death	<ul style="list-style-type: none"> <li>• Having cancer made me intimately aware of my own mortality</li> <li>• I have a sense that life is short and precious</li> <li>• Making friends who were also cancer patients meant I experienced the death of others more frequently</li> <li>• I have a matter-of-fact view of death</li> </ul>

The first subcategory, constant sense of danger or uncertainty, was described by participants as persistently feeling unsafe or in danger and having a constant sense of uncertainty in life. The lack of safety or imminent danger participants frequently spoke of was related to getting cancer again. Individuals expressed that having cancer in the past and knowing they can get it again makes them feel like danger is looming over them, ready to strike at any moment. Janna described it by saying, “I think you just never



feel safe or out of the woods, or out of danger, after all that. You can't... umm, I'm sure most people don't feel like they're in danger all the time, but as a survivor you just never really feel safe." Survivors described that feeling extending to an overall sense of uncertainty about their lives; they explained that when they had active cancer they had to live with being uncertain about whether or not they would live through the disease. The individuals described that going through such a long period with such a marked uncertainty caused them to always have that sense of uncertainty, even after the cancer was in remission. Janna went on to explain:

Cancer survivors just have to get used to living with uncertainty all the time... other people get the luxury of feeling certain about, feeling this certainty about their lives, whether it's true or not. Not so with survivors, you just have to get used to being uncertain about everything, all the time.

Another way in which survivors felt their outlook and attitudes were different was their level of maturity. Survivors in each group mentioned having a sense of being "over mature" than their peers in many regards even though they "feel behind" their peers in many ways. Participants described that going through something so huge, like surviving cancer, made them more steadfast in how they experience small problems in life; many of them made the comment that they learned not sweat the small stuff. Gabriella mentioned, "[it's] stupid to sweat the small stuff when you've got big stuff, when you know what it's like to have real problems", and this sentiment was shared by each focus group. Members described not getting upset or stressed over "little things" like flat tires, bad days, getting a cold, and so on, and they described finding their same-age peers' tendencies to stress over minor issues annoying. Gabriella described it by saying "I think everyone else is a big baby about their health now that I've gotten over

cancer. Like my best friend is a big baby about getting her blood drawn, and I am not even fazed by that. Or like if I have the flu, I'm like, whatever, big deal. Or a flat tire, who cares?" Frida responded, "That's so true! I'm like, ooh a runny nose, big deal!" Janna made a similar comment; "little things don't bother me, like we said about getting shots or if I have a cut or sore throat, that doesn't bother me."

Participants described that having to grow up and gain maturity so fast is not always a good thing; while it does help them to deal with or process minor stresses in an adaptive or healthy way and contributes to them being more calm, level headed, or accepting than their peers, they also felt like it distances them from others as well, and is just another way they are different, or "abnormal". Gabriella and Edgar discussed this difficulty: Gabriella stated, "So in some ways, it's like I'm over mature in areas like that, and it only makes, like, umm, it makes, the, the distance between me and other people my age even greater sometimes... harder to connect when we're on different levels on so many things." Edgar responded, "I can relate to that... the being over mature in some things. When you have cancer when you're a kid it makes you grow up really fast. Like you've gotta go from 0 to 90 miles an hour real fast because you've gotta deal with some really heavy things that most kids never do." Participants mentioned that this maturity and perspective was gained at the cost of normal development at times and because they were dealing with "big" things instead of doing the normal kid/teen/young adult activities, the end result was a survivor that is over mature in some areas and under mature in others.

The next area under outlook and attitudes that survivors discussed was expectations or knowledge, which was closely related to the survivors' sense of maturity. They described the subcategory of expectations and knowledge in the following ways: (1) having more knowledge of life than others, (2) expecting bad things to happen, (3) having to think about different things than others and, (4) being more realistic or less naïve than other young adults. The survivors described that the experience of being a cancer survivor gives them more “insider” knowledge of life, and because of their cancer experience they have an understanding and awareness that bad things can and do happen. They described that this set of knowledge and expectations contributes to a “more realistic” view or outlook than their peers. Dave stated, “It definitely changes the way you look at things, we have a more, a more realistic viewpoint, not all sunshine and dreams when we think about the future, unlike other people our age.” Alice chimed in, “Yeah, like some of the others have mentioned, I have a very different view of my future, of my potential life I will have, than other normal people my age. I have to think about things that no one else does”. Gabriella described this knowledge by saying:

It gives you a different perspective than other people your age. Like you know more than them sort of, you know how life can be, how it can change so fast, how it could even end maybe, so you just, well, you have more knowledge and it's kind of a curse. It makes you do things differently than maybe you should, it makes you understand the whole world differently. Maybe better, maybe worse, I don't know.

Ingrid described it as having “seen the other side”; she said, “It's like, you've seen the other side, or something. Like you get a ‘been there, done that’ Girl Scout badge, and it just gives you all this weird experience that no one else has.” The participants mentioned

that having this perspective from their experience of cancer can make them expect bad things to happen; they see this as a just being realistic or planful, or “living in the real world”, however, they acknowledge that others might perceive them as being morbid or gloomy. Alice described. “Not only do I know that bad things can and will happen, but I have to think about the repercussions and plan for if or when these things do happen” and Brenda, a preschool teacher, offered the following example:

I look at all the preschoolers in my class... and I'm like, just dreading that anything bad might happen to them, because, because I know that it can I guess. It seems like other people live like nothing bad can happen to them and that bad things are super rare, but, yeah, when you've had something like this happen you know that not only CAN bad things happen, but they DO.... Definitely a lot of time is spent planning for the whole what if something bad happens, what's my 'game plan' going to be.

She goes on to say, “Most people aren't that doom and gloomy, they think it's ridiculous or dramatic or morbid, but when you've been there, you know it's reality, that's all.”

Participants reported that as survivors they had different things to think about compared to their peers, which contributed to the necessity of being more realistic. They describe that concerns about their health, potential recurrence, insurability, savings, fertility, self-care, and mortality are part of their regular thoughts and that other young adults do not think about these same things “because it's not their reality”, as Janna put it. Participants felt that the things on their thought agendas were very different than the normal young adult, and additionally, not only did they think about different things, but they described thinking about “normal” things differently than their peers. Lina explained:

Survivors just have to think about different things that normal people don't have to think about, and umm, well you think about different things AND you think about normal things differently. Well, you think about different things... like we already said, like health insurance, really what other young adult is thinking about that? Or all of their health risks, or if a disease is waiting right around the corner for them? People aren't concerned with that, you don't have to be when you're normal. But when you're a survivor, you do. And not only that, but uh, even normal things that other people ARE concerned about, we think about too, we just have to think about them differently... have a different perspective. Like dating, school, getting a job, moving out... we just have, I don't know extra things thrown into those arenas that make them a little different for us, like moving out is different because of the relationships we have with, and need we have of our parents... see? Just different.

In further explaining how their overall outlook and attitudes were affected by being cancer survivors, participants described that along with their thoughts, their priorities changed too. After cancer, survivors explained that now things like insurance or fertility issues are not only thoughts they have to be concerned with, but are also prioritized in their lives as survivors. Some participants detailed that while normal young adults may think of these things from time to time, they do not have to prioritize them as survivors do, and that is one of the distinguishing differences in overall outlook and attitudes.

Finally, the last subcategory that emerged under outlook and expectations was survivors' sense of mortality. Many of the participants described having different outlooks or opinions about death and a more intimate awareness of their own mortality. The survivors explained that when going through the cancer experience death is a real possibility and it becomes something you think about and are aware of in a very matter-of-fact sense. They discussed having to be more accepting of the realistic possibility of death after having a near-miss experience with it. Not only did they have to consider the

possibility of their own death, but they mentioned that during cancer they made other friends in hospitals and patient programs who had cancer as well, and some of them died. The participants described that the intimate experience of knowing they could die and having people they knew die affected how they feel or think about death. Frida mentioned:

You're more likely to have known people to have died... you make friends with other people with cancer and sometimes they die, so you like, accept death. Well, not accept it I guess, but you know what I mean. It isn't as big of deal when you've had to experience it all up close and personal a lot.

Gabriella agreed and added her own feelings:

Not only do you have more knowledge and experience with other people's deaths, but... you know your own mortality, your own life will end at some point. I don't think most people our age think about that. Or if they do, I don't think, they don't really believe they can die, you know what I mean? We know that we can, that makes it different.

She explained that this is a realistic view for survivors, but that normal individuals do not have that same experience:

Things that would be scary or unusual for other people are normal for you. Like, to think about death, or bad things happening, or worrying about getting a fatal illness, and all that. Most people don't think about that stuff, and when they do, it's like a big deal, something terrible. For us it's just normal and easy to think about that stuff. You handle things like death or other bad news differently than other people.

Survivors reported in general that they think about death more frequently than the normal population and they have a sharp awareness or understanding that life is short and can end at any time. Comments like: "you know how life can be, how it can change so fast, how it could even end maybe", "maybe it's morbid, but I think about things about death and how short life is" and, "I am intimately aware that my life is precious

and I, or anybody, could die at any time” characterized how survivors felt about their own mortality.

Overall, the category of outlook and attitudes came up consistently in the data, with participants noting many differences in their outlooks compared to their same-age peers who never had cancer. Differences that were discussed included a constant sense of danger or uncertainty, a different maturity level, different expectations or knowledge of life, different priorities, and a clearer awareness of mortality.

**Myths about survivorship.** A particularly interesting theme that emerged was the area of myths about survivorship; individuals spoke about widespread inaccurate beliefs about survivorship with a tone of disdain and frustration. They explained that being a survivor is thought of as this positive, uplifting, or liberating experience, however, the participants did not identify with this conceptualization of what it is like to be a survivor. The participants explained that the whole experience of cancer is only bad and unpleasant, and others try to focus on the “positive aspects” of it when in reality there are no positive aspects. They felt that there was no such thing as “the bright side of cancer survivorship” or the “benefits of survivorship”, and that these were merely myths established for the benefit of others, not the survivors. They described that by sharing the “truth” in the focus groups they had “ripped the pretty mask off of surviving cancer”. Alice explained that “The whole ‘upside of cancer’ is a myth. People have to talk about that stuff, the cheery stuff, because the truth, that it’s just terrible, unfair, awful, is too much for people”. Another individual described, “There’s not a silver lining or a bright side, it just flat out sucks. And that’s okay. Just let it be a bad thing, because it is.”

Gabriella replied, “Yeah... but people can’t accept that...” and Frida chimed in, “So they gotta turn everything into some positive message, right?” David described that he felt that people needed to hear the “chicken soup for the soul version” or the “we have overcome version” because the truth, that cancer is only a bad thing, is uncomfortable or difficult to accept. The general feeling from survivors on the matter was that cancer was a negative and terrible experience, and going through survivorship made it clear that people do not know how to handle when things are just bad; they need to turn things into a positive message whether or not that is true or helpful. As survivors, the participants seemed to have an understanding or belief that some things in life are just bad and that it is okay for bad things to exist, and believed that relying on uplifting “hero story” versions only takes away from the truth of the experience of survivorship. David went on to say that those versions only exist “to make people who are on the outside looking in feel better.” Individuals brought up the example of cancer movies or stories, and explained that those “after-school special” movies or stories did not really capture their experience and they found themselves unable to relate to them. They did describe, however, that other people in their lives seemed to find those accounts and stories helpful or meaningful. Survivors themselves, however, did not feel like they could identify with them, and described stories depicting cancer patients or survivors as being “either too positive and uplifting or too sad and dramatic”.

The consensus of the survivors was that it would be better if everyone knew that those sentiments were just myths, more for the benefit of bystanders. Participants explained that these myths only create unrealistic expectations of survivors and color all



survivors as strong and optimistic heroes. Brenda described that it is important for people to have a better understanding of the truth of cancer survivorship because the myths only make it more difficult for survivors:

That's important I think, because you think you're the only person who doesn't feel all strong and cheery and all those things, but then you start talking to other patients or survivors and go on to chat rooms and stuff and you realize that no, other survivors feel the same way you do. So you start to realize that it's not that survivors really are like this [like the movies], it's just how people want them to be and they're just trying to fit the mold.

The survivors believed that these positive depictions of cancer and survivorship are perpetuated because people have an underlying need to focus on positive things whether those things are true or not. While survivors expressed understanding this need, they reiterated that these “myths” injected more difficulty into the experience and process of coping with survivorship because they reinforced inaccurate beliefs about survivors or created unrealistic expectations of them.

**Expectations of survivors: Being the “good survivor”.** A similarly fascinating finding in the focus groups was the theme of participants feeling as though there is a prescribed “script” or “proper protocol” for being a survivor; and each survivor admitted to having familiarity with this script. The participants explained that there is a very clear set of standards for behavior as a survivor. Ingrid stated, “You get the sense that there IS a right way, is a way people expect you to be as a cancer survivor, and it makes it hard.” The focus group members described that doctors, family, friends, and society in general expect cancer survivors to be a “good patient” and a “good survivor”. When asked to describe what it meant to be a “good survivor”, participants explained that the

expectation is for survivors to not complain, say they are doing well regardless of any problems they might be having, smile and be positive, put a brave face on, and talk about how they are succeeding in spite of surviving cancer so that everyone can then feel good about them and pat them on the back. They described that this exchange is “proper protocol” and that everyone knows and abides by the script. They explained that others reward them for being a “good survivor” by responding positively and praising their strength, bravery, and courage. The participants reported that they attempt to live up to others expectations because they are rewarded and encouraged when they do, and they do not want to disappoint the people in their lives, even though these expectations put quite a bit of pressure on them. When discussing the definition of “good survivor”, participants said the following:

Brenda: Oh, what you’d expect I guess...

Alice: Someone who doesn’t complain, suffers any pain or discomfort in silence, keeps a brave face on, smiles, says they’re doing good when people ask, talk about the things in life they want to do so people can say, “wow, cancer survivors always are so optimistic and brave, they just go out there and really try to live life to the fullest”. They want to see you as a fighter....

Dave: And ‘fighter’ ends up meaning those things. Nobody likes their ‘champion’ grumpy with a bad attitude.

Callie: That is so true. People want a friendly, brave, gracious survivor, not an irritable, angry one.

This same set of participants continued to discuss getting attention for following the “script” or “protocol”:

Alice: ...Everyone wants the survivor to say they’re doing okay, they’re good, they’re hanging in there or whatever, so you’re doctor or parents can fawn all over your bravery, strength, and courage, right?

Dave: That seems to be proper protocol (laughs).

Callie: Yeah, that's how the script is written. You say some variation of you're doing well, and your doctor starts beaming and telling you how impressed he is with how positive or strong you are, and you're mom says something like "yeah, she's a real trooper, she's doing great". Or nurses or just people in general say things like "cancer survivors or cancer patients are some of the strongest or most positive people" there are. (Laughing) Now, you tell me what you're supposed to say to that? Are you going to tell them about how you're having a hard time worrying over your health or how you've been a bit down? No...

Alice: Yep, everyone knows proper protocol is to give them what they want to hear, because survivors are supposed to always be strong, that's what they give attention and praise for anyway.

Dave: Yeah, you could ask anyone who's had cancer and they'll tell you the same thing.

The survivors described that they tried to live up to others' expectations of them, but sometimes it was a difficult or impossible task, and if they succeeded at it they still lost because it left them feeling misunderstood or unsupported. They described this system of expectations for behavior and interactions as setting the standard for the kind of survivor they are supposed to be, and added that there is a lot of pressure to measure up to those standards. Janna shared how difficult this has been for her:

It's just hard, there's a lot of pressure to umm, just deal with it, get over it, and be a good example of like, a storybook survivor that everyone can be proud of. You don't want to be this person that's dealing with it badly even though they survived, and have people feel disappointed in you or like you're not doing it right, whatever right is. Just, putting on a smile and dealing with it and trying to focus on the positive things, and just appreciating you're alive. And I do, I really do, of course I do, but you know, it's, sometimes you feel other ways too and that's harder to share with people because they don't get it.

In general, the survivors perceived the existence of an unspoken, unwritten but very clear set of rules and standards for how they should behave as a “good survivor”; they felt that all survivors are aware of these pressures and expectations. Many mentioned that they do their best to live up to these expectations because they can tell that people prefer it; they described that they know what the expectations are because everyone around them rewards or encourages them for behaving those ways, and appears to be uncomfortable or unhappy when they do not follow the “good survivor script”.

**Social life & interactions.** A common theme in the focus group interviews was survivors’ social lives and interactions; many of them described that surviving cancer changes how others treat them and how they react in social situations, and can cause some difficulties in general. Survivors ultimately described feeling like it is hard to be close to others and form lasting friendships and meaningful bonds with people around them, though they admitted to desiring such relationships. Five different subcategories of social life and interactions were identified by the participants as affected by being a cancer survivor: (1) how friends and family experience my cancer and survivorship, (2) people’s reactions or interactions with me as a survivor, (3) making friends and connecting with others, (4) I have less sympathy for others’ problems, and (5) I feel like only other survivors can “get” me,. The subcategories and brief explanations for the category of social life and interactions can be seen in Table 9.

Table 9  
*Category of “Social Life & Interactions”, Subcategories, and Explanations*

Social Life & Interactions	How friends and family experience my cancer and survivorship	<ul style="list-style-type: none"> <li>• Other people in my life were affected by my cancer; it was hard on them too</li> <li>• My friends and families are like “survivors” too</li> <li>• The shared experience of my cancer and survivorship affected my relationships with others</li> </ul>
	People’s reactions to or interactions with me as a survivor	<ul style="list-style-type: none"> <li>• People are “weird” around me because I am a survivor</li> <li>• People treat me like an invalid and baby me, or they do the opposite and expect me to be a superhero</li> <li>• I get the “sympathy vote” from others</li> </ul>
	Making friends and forming connections	<ul style="list-style-type: none"> <li>• It is hard to make friends as a cancer survivor because people treat me differently</li> <li>• I have a tough time relating to normal people</li> <li>• It is a dilemma for me to decide whether or not to share my experiences with others</li> <li>• I am on a different track and have different experiences than my peers</li> </ul>
	Less sympathy for others’ problems	<ul style="list-style-type: none"> <li>• Surviving cancer makes me view other people’s problems as minor</li> <li>• I get frustrated with others and feel like they blow small problems out of proportion</li> </ul>
	Only other survivors “get” me	<ul style="list-style-type: none"> <li>• I feel like only other young adults who have survived cancer can really understand me</li> <li>• I feel most supported when I am around others like me</li> <li>• My status as a survivor makes me feel alienated from other “normal” people</li> </ul>

First, survivors acknowledged that it was not just them, but the people around them, like family or close friends, who were affected by their cancer experience. They described that the experience must have been difficult for the people around them too; Jenna said simply, “I think it’s hard on them” and Brenda described it by saying “I suppose your friends and family members are survivors of a sort too, but it’s different”.

Callie added, “I know what you mean, it’s hard for them too, and they probably take it even worse, man I hated watching my parents go through that, it was painful to watch, you’d think it was them who had the cancer, but it is... different....”

It was evident that survivors felt that the people around them underwent a difficult experience during their cancer diagnosis and treatment, and acknowledged that it was tough for everyone involved. This shared experience of cancer had both negative and positive implications according to survivors; while at times they felt it brought them closer to those around them in some ways, they also felt like it fundamentally changed those relationships and it made it difficult to “just be normal” with others after that. This was further explained in the next subcategory, people’s reactions to or interactions with survivors.

The participants explained that once they became a cancer survivor, it forever changed how others interact with them. They described that people’s reactions to or interactions with them as survivors are not the “normal” interactions of people, but some altered thing that frequently contains pity or awe. Survivors consistently reported that when other people know that they had cancer, it makes them “weird or different” around the survivors. Janna explained, “Being a survivor has affected my social life... people just react differently to you when they know you’re a survivor. They’re, I don’t know, more scared of offending you or think you aren’t interested in the normal things, like you’re handicapped or something.” The following exchange between Nicole, Katelyn, and Lina further explained the problem:

Nicole: When you tell people about that part of yourself, that you're a cancer survivor, they just, act differently around you. They don't act normal anymore.

Katelyn: Yeah, I'm familiar with that one. They can act like you're broken.

Lina: Or they're really sad for you and they feel sorry for you. Or act weird, like they're uncomfortable now and don't know what to say to you.

Nicole: And you can feel the change, in um, the change in how they see you. Like they feel guilty for being healthy or something and feel like they don't want to share things with you because they're not as big of a deal as you having cancer.

The participants shared that other people treat them like they are either fragile, delicate invalids or as though they are super heroes. The following quote from Brenda described what this is like:

When I tell people I survived cancer, I, I just get a different response. Like he said, it makes people feel weird around me, want to stop talking because they don't know what to say, or worse, they tell me how strong and brave and courageous I am. Because having some terrible thing outside of my control happen to me randomly does not make me brave or courageous. I'm not saying that I want everyone to let me cry on their shoulder, but people expect me to be some emotionless superhero as a survivor, but they expect my mom to have gone through hell and back and barely made it, (laughing). I get everyone's weirdness or *atta'girls*, and neither one are really helpful.

Edgar described it by saying:

Either they ignore you because they don't know what to say to the 'cancer victim', or they're all positive and stuff when there's no reason to be, or they're babying you or something, no one just talks to you straight, no one like, wants to really know what's going on. Like either they have low expectations of you, or they see like, other cancer people on tv like lance Armstrong running races and stuff and starting charities, and they're looking at you like, what are *you* doing (laughing), why aren't *you* climbing mountains for cancer awareness and stuff?  
It's like you're either a baby or some super hero, a super survivor (laughing), there's nowhere in the middle you can be.

The participants described that it can be really uncomfortable when people react so strangely toward them, such as behaving as though every little thing they have done is a big accomplishment:

Gabriella: And when I do happen to like, see people that I knew in high school, I'm just, really embarrassed because I don't have a lot to say for myself, umm, and, I, umm, it's even worse you know, because when people find out that I'm living at home, no one gives me hell for it, like it's okay or expected or whatever, I think, because I had cancer.

Frida: Oh yeah, it sucks to be constantly getting the sympathy vote, like you're held to different standards or something.

Edgar: Oh yeah, I know about that, like you've got a different standard and if you do anything good it's like you won the Olympics or something. I guess, on one hand it's nice to get that attention, but when you think about it it's a little embarrassing or stupid to be getting a lot of attention for not really doing anything that like, that good.

Gabriella: Yeah, exactly the way you just said it, they don't expect much of you and then make a big deal about nothing. You get used to getting a lot of attention for little things, and then if you were to like, go to school or something or get a job, other people don't act like that, don't treat you like that and it's a little bit of a, umm, a shock sort of, but it's probably a good thing, to be umm, treated normally, but it's like, everything has already made you umm, lower your standards of yourself because the, uh, people in your life have like made you believe they should be lower. But I don't think anyone knows that's what they're doing or anything, or anyone's trying to be like that, it's just, umm, happens I guess.

The participants described that how people react to them contributes to the next subcategory, making friends and connecting with others. The participants explained that it is much more difficult making friends and really forming close relationships with others when they behave so strangely toward them, as evidenced by the quotes above. However, there are other elements that cause making friends to be difficult for survivors; they explained that it is hard connecting with others when as a survivor one cares about



different things than “normal” people and/or is on a different track or timeline than his or her peers. Survivors reported that having such a different background and set of experiences than normal people, or being fundamentally different from others, makes those close connections hard to establish. Individuals expressed that friendships they had before the cancer were changed and they had lost touch with those people, and when they do see those old friends they act strangely or with pity toward the survivors. However, making new friends is equally difficult because as was discussed, when people find out about survivors’ cancer experience it can change the dynamic of the interactions and make the survivors feel even more abnormal.

Survivors described feeling as though it is a dilemma whether or not to share their cancer experiences with others or just keep them to themselves. Gabriella offered the following explanation:

And the friends I make at work or church and stuff who didn’t know me during the cancer, we kind of make acquaintances and it would just be weird to share that kind of, that deep of stuff with them, you know. And if you do, they just don’t know how to respond.... So I guess it just sucks, I mean I can’t really be close to the people who knew me before because they look at me and only see a teenager with cancer, even though that was forever ago, and I can’t get too close to new people because they would just be weird if I tried to share my baggage with them, it would scare them away. Relationships are just hard after you go through something like that I guess. It’s like you want to be treated just like another normal person, so you don’t want to tell them about that part of you, because then they won’t treat you normal, but on the other hand sometimes you want to talk about it because it’s a big deal, a big old part of you that’s not going anywhere, but you don’t have close friends, so there’s no one to really do that with. It’s like, a catch 22. It’s not going to pan out well, it’s just going to be weird and uncomfortable.

In addition to it being difficult to handle how other people react to them, survivors described that it is also hard for them to personally relate to their peers. They

expressed feeling as though normal people can tend to blow small problems out of proportion and get very upset over small issues. The participants described themselves as having less sympathy for others' problems after having survived cancer. The following exchange between Frida and Gabriella captured this sentiment:

Frida: You just think other people are like, being stupid if they think their problems are such a big deal. Maybe that's good and bad, right, because it's good that we feel like little things aren't such a big deal....

G: But it makes us really crappy people to be around if we're not sympathetic to other people's problems...

F: Exactly, that's the bad part I was going to say (laughing).

G: I try not to ever say anything like that out loud to the people in my life, I keep it under wraps, but I definitely find myself thinking it and getting frustrated with people sometimes.

Survivors reported feeling like only other cancer survivors really "get" them, which was the fourth subcategory in the area of social life and interactions. The participants explained that because being a survivor makes one so very different from "normal" people, it is almost impossible to feel truly supported and understood by their normal peers. Survivors explained that seeking support from other survivors has been a lifesaver for them, and only when they are around other survivors do they feel like they are in the presence of people who "get" it and understand how different life is as a survivor. Brenda stated, "Well, I guess it's like anything... you have to go through it to really understand it." Frida mentioned, "Normal people don't get it. It's not their fault, but it does kind of make you feel alone", and Edgar added:

Yeah, it's like that. Like how can you really be close to someone when they'll just never get it? It's like coming back from a war and everyone's telling you you did a good job, but you know only your buddies who were

with you, who saw it too really get it. So other survivors, like the people you meet at hospital groups and stuff and make friends with when you've got cancer, they're the people who get it the most probably.

Janna explained that she believes everyone needs to feel like they are part of a group and understood, and that other survivors are the only people who can really provide that; she stated, "cancer can make you feel... alienated, umm, like, makes you not a part of the normal people group, other people your age, so to find a group of people or even just one person, who gets you and has *been there* is good." Owen mentioned that support groups or online meet-ups are often better than making "normal" friends; he said that it is "kinda cool being around other people who have had the same experiences and just uh, get you better." Katelyn chimed in and said, "Yeah, I feel like most of my friends live online, in my computer.... Because they are the people who just, get me the most, get it overall".

Based on the information participants provided in the focus groups, it was clear that they experience a difficult time making friends and forming close relationships with others who they perceive as "normal". They described feeling very different from normal people and these differences make it hard for them to relate to their peers, and hard for their peers to relate to them. They found it hard to be sensitive or sympathetic to "normal" people's problems at times, though they felt like it was wrong, they expressed that other people make a big deal out of small problems, and they find that silly and frustrating. Because of all of these relational difficulties, survivors feel like other cancer survivors are the only people who can truly understand or "get" them. The members described feeling at their best when they had opportunities to be around other survivors,

however, they also explained that these opportunities can be rare because there is a dearth of organized support available to survivors.

**Lack of organized support for survivors.** Though all of the participants described thoroughly enjoying and relying on support from other survivors, many of them expressed frustration about the limited quantity and access to such groups, and felt as though there is an overall lack of organized support for survivors. The participants discussed that while there were many supports available to them when they were active cancer patients, those resources and services dropped off when they became survivors. They expressed frustration at this because they feel as though there are still many of the same problems that exist for survivors, therefore there should continue to be support services available. Gabriella stated:

You've got all these services when you've got cancer, but okay, now I'm not a teen with cancer anymore, now what? I still have to think about recurrence, or being able to have kids, or getting health insurance, or whatever, all of these things are different in my life because of cancer, but there's not a lot of umm, guidance or support or whatever... once you don't have cancer anymore. There aren't a ton of groups for when you are, like, when you become a survivor instead of a patient.

Nicole, Lina, and Marta had the following discussion about the lack of support groups as a cancer survivor:

Nicole: But it's tough because there aren't a ton of groups or anything. You really have to seek that sort of thing out. No one just, gives you that information or anything.

Marta: Yeah, it would be nice if it was more known, or available. Like if when you went into remission your doctor hooked you up with a support group or something. They always tell you to go seek out that stuff, but you're right, it's not like it's everywhere just waiting for you to come join.

Lina: Yeah, it seems like a lot of the time you have to make it happen yourself. When you are a, um, when you actually have the cancer your doctors and stuff do give you support group information and stuff, like I know MD Anderson has one and stuff, but what about when you don't have cancer anymore? There's not a lot of that kind of thing for survivors.

Nicole: That's why the online group is awesome.

Lina: Oh it is, it's great. But it's rarely an in-person thing, it would be cool if it was. When I had the cancer, there were always so many events and support and stuff, I felt like I made friends all the time with so many other patients fighting the same battle. But this is kind of a battle too right, sort of? So it would be pretty cool if all the same support stuff still existed for people in our situation.

It was clear through these conversations that group participants felt that there are not enough support resources available for when they moved from having active cancer and being a patient to being in remission as a survivor. Survivors described a desire for more in-person young adult survivor support groups, as they felt that they get the most out of this type of support. It should be noted, however, that although participants all agreed that support from other survivors is the best kind of support, no one had followed through with starting up in-person groups with their online support group contacts. Survivors were able to conceptualize the problem and what helps to "fix" the problem, but they do not make the leap to working on solutions to the problem.

**Romantic relationships & dating.** Another clear theme that emerged from the focus group discussions was difficulty with romantic relationships and dating or marriage. The survivors explained that, similar to establishing relationships with friends, forming romantic relationships is difficult as a cancer survivor. The participants described wanting to date and feeling lonely, but when it comes to actually dating they felt like getting involved with someone romantically was difficult and a lot of

responsibility. The group members described feeling “behind” in this arena, feeling like it is hard to date because sharing and conversations are a challenge and it is difficult to meet like-minded people, and expressed feeling like it might not be fair to a potential partner because being a survivor comes with so many problems. The survivors who were single described feeling uncertain of whether or not they would ever find love, and questioned if anyone would ever be able to love or understand them. In addition to all of these concerns, survivors added that the area of sex and intimacy is a challenge as well. These subcategories and explanations are noted in Table 10.

Table 10  
*Category of “Romantic Relationships, Dating, & Marriage”, Subcategories, and Explanations*

Romantic Relationships, Dating, & Marriage	Desiring a relationship; loneliness	<ul style="list-style-type: none"> <li>• I want to be in a relationship or dating, I am ready to date</li> <li>• I feel like something’s missing in that area of my life</li> <li>• I am scared of being alone</li> </ul>
	Relationships require commitment and are a big responsibility	<ul style="list-style-type: none"> <li>• The idea of such a big commitment is scary as a cancer survivor</li> </ul>
	Feeling behind or inexperienced	<ul style="list-style-type: none"> <li>• I feel behind when it comes to dating, I am coming “late to the game”</li> <li>• My inexperience makes me unsure of myself and nervous about romance</li> </ul>
	Hard to date	<ul style="list-style-type: none"> <li>• Meeting people is difficult</li> <li>• It is hard to share myself and my experiences with someone, difficult conversations to have</li> <li>• I have a lot of baggage</li> <li>• I have an obligation to “disclose” certain things about myself as a survivor, but it’s hard to know when to do that</li> </ul>
	Will I ever find someone, or even <i>SHOULD I?</i>	<ul style="list-style-type: none"> <li>• I wonder if I will ever fall in love or be married, will anyone ever want me?</li> <li>• Even if I do find someone, is it really fair to a potential partner to have to be with someone who has these problems?</li> </ul>

Table 10 Continued

Sex and intimacy*	{ <ul style="list-style-type: none"><li>• The prospect of being sexually active or physically intimate with someone is scary or embarrassing</li><li>• I feel like people can't be attracted to a survivor or see me as "damaged goods"</li><li>• I just want to be seen as a normal and attractive woman</li></ul>
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\*The sex and intimacy subcategory was discussed by just one focus group that consisted of only women.

The participants who were single expressed that they really want to date and find love; some mentioned being lonely and having a fear of being alone. Gabriella stated, "These last few years... I've wished I had a boyfriend", but explained that it is a daunting task. Lina explained that she really wanted love, marriage, and to settle down, but that it was different for her than others. She described that dating and pursuing those things seems overwhelming when one feels like they are behind in that area, but she admitted that the idea of being alone was really scary too. Janna agreed, and stated that before she recently met someone in church, she was "super ready to get into dating" but felt like she was "late coming to the game".

Many of the participants described feeling inexperienced or "behind" in the realm of dating; some of them connected it to being delayed due to their cancer experience, others described being delayed due to their parents' influences, and others attributed the delay to feeling uncertain or nervous about dating. Gabriella stated, "I don't know, I just kind of feel like I got left out of the time of my life where I should have been dating a lot, and maybe I missed what I was supposed to learn, and I feel like an idiot now, I don't really know how to go about it." Participants also described the

prospect of dating as daunting, because they felt it is a big responsibility to date someone, and even more responsibility to be married, and that contributes to a sense of uncertainty about getting involved romantically. One participant, Edgar, reported that he had a girlfriend who wanted to be married, but as a cancer survivor the idea of marriage was very scary for him because he said to think about all the ways in which he was delayed in his personal development and consider whether or not he was truly responsible enough for marriage, even though he felt that he was of an age that is typical or acceptable to consider marriage.

Not only did survivors express feeling behind or inexperienced and that relationships are a big commitment and responsibility, but they also reported feeling that dating or romance was just difficult. Many participants mentioned that it was hard to meet people, and even if they did, it was even harder to get close to someone and share themselves with him or her. Janna described:

For me, I, it's a lot of things that make my love, love life different, but mostly I find it hard to date. I mean, I've been seeing this person for a little while, so it's not like I haven't dated, but it's um, having a love life is just tough. It's umm, difficult to get really close to someone. If I keep seeing him I'll have to tell him that, the whole story. That I had cancer, multiple times even, and that because of it, there's a chance that it'll be harder for me to have get pregnant when I'm ready for that sort of thing. That's a hard conversation to have, because like, when do you tell someone that? Too early and they think you're crazy and over-sharing way too much and it just scares them off because they're not looking to be that serious. But, too late and it's like you've been hiding something, something big, from them. And that's just as bad.... I've got this whole other thing to deal with, this umm, bomb to drop on them and I don't know, how do you really know the right way to do that? It's, just, just hard I guess.... I don't think other people have a tough time with this; it's supposed to just be, kind of come naturally and be exciting I think.

Edgar expressed feeling similarly about sharing himself in a relationship:



When it comes to being, umm, being close to someone and sharing about your past and stuff, you can't just come out and say, like "I've had brain tumors, yeah, twice actually, they cut into my brain, mmhmm, pass the ketchup please." (Laughing) How are you supposed to have that conversation, and if you do they start feeling sorry for you, and that's not how girls wanna feel about the guys they're with, they want their man to be strong and be able to take care of them, they don't want to be wondering if he's gonna get sick and need to be all taken care of and stuff.

Gabriella also used humor to express how difficult dating is:

Sooo, like, can you imagine me trying to date someone and being like, so yeah I had this cancer, and oh, people who get it once are more likely to get it again, and um, you know if we're together you might have to umm, take care of me and stuff, umm, and by the way, I don't know if I can have kids very easily, I umm, I might be infertile, but that's okay I have these frozen eggs they're keeping for me somewhere,, no problem! Haha, you see why dating isn't as easy as they make it seem? (Laughing)

One participant, Katelyn, described being a cancer survivor and trying to date as a big mess, and stated that having cancer in one's past is "a big old skeleton in your closet" and a lot of baggage. Lina, Nicole, and Katelyn discussed the responsibility to disclose these details about themselves to someone they would potentially date:

Lina: Yeah, it's not certain that I'll get cancer again, but it something I have to consider, and umm, in the interest of full disclosure, I uhh, have a lot to 'disclose' I guess, in a relationship

Nicole: I know that feeling, and it's like, when do you tell people those things. It's hard to figure out how to move through those uh, conversations. How do you say those big things, when do you say 'em, etc.

Katelyn: Yeah, and a little you don't want to tell people that stuff almost at all, because you just want to be looked at like a normal girl, you want someone to just like you and not feel sorry for you or start thinking about uh, what a risk it is being with you and whatever. So it'd be great to never even tell people about your cancer, sometimes, but also, uh, it's a big thing. A big uh, thing in your life and stuff and you probably should share those parts with people right?

Frida, a participant who was involved in a long term relationship, explained that even once she got past all of those parts and felt stable in her relationship, she encountered other difficulties. She described that it is hard for her to communicate with her boyfriend about her cancer experience because he does not understand; she mentioned that he does not see why it is still a problem for her if it occurred a long time ago:

My man, he and I don't really talk about it. The times I've tried to, he's all like, that was long time ago, you were like 8, how do you even remember? Like it shouldn't be a problem, not a real problem for me, like it's stupid. He, umm, just kind of acts like I'm trying to, like, get sympathy for something that's not real. So, yeah, I don't really talk to him about it, but I wish I could.

It was evident that the participants felt like dating and romance are difficult endeavors for cancer survivors; both single and involved individuals alike expressed challenges and difficulties. Many of them questioned whether or not it is “fair” to “put someone through that”. Alice stated, “Is it fair to subject anyone to my neurotic worries, and if the cancer does come back again, is it fair to make someone go through that with me? It's just, it doesn't seem fair to do to anyone.” Brenda agreed with her and added:

I felt guilty and overwhelmed when I was dating my husband and I knew it was going in that direction. I felt like, man, most people just get to think about whether or not they love someone and that's all, but I thought, like, I have to think about more, like, is it fair to him to marry a girl with so much, baggage. Emotionally and physically, just, baggage.

These difficulties left some of the participants wondering if they would ever find a partner or someone who could love and understand them. Alice asked, “Will I ever get married? ...Can somebody really understand me and love me, will I know how to communicate my experiences to them, or will I only be able to relate to someone else

who had cancer?" Ingrid stated, "I'm kind of beginning to think that it's not gonna happen for me unless I find a guy who's been through this sort of thing too so gets it." Another participant, Janna, summed it up by saying, "Yeah, I get it. It's not easy finding the right kind of guy who is umm, supportive and understanding about your cancer experience and its side effects, but also not hung up on it. It's all... it does seem harder than it should be, the dating, the sex stuff, everything."

The survivors described that the topic of sex and intimacy presented some challenges as well; especially for those survivors who reported having physical effects from their cancer experience. Ingrid, a young woman who had a leg amputation as part of her treatment, described sex or physical intimacy as stressful or embarrassing. She brought up the topic and offered the following insight:

I don't want to be, umm, inappropriate or gross anyone out, but umm, what's a polite way to say it... being, umm, physical, or umm, intimate with a guy isn't very easy either.... Apparently guys aren't into leg stumps (laughing). And when I've been with a guy and it has gone in that direction, well on top of not really feeling desired and being really self-conscious about how I look, I feel like he's, like he feels sorry for me or something, like he's just trying to umm, do me a favor by being with me or something. And he's really weird and uncertain about like, if I'm going to be hurt or have umm, limitations, let's say.

...Something that I would want to be kind of special and meaningful is more stressful and weird. Like, I just want to be seen as a pretty girl, to be desired, and to be normal, but I feel like guys look at me and just see my disease.

It was interesting to note the topic of sex and intimacy was broached only in the focus group that was made up of women. It seemed to be the case that the nature of the female-only group was such that this sensitive topic was easier to discuss for the participants, however, even in this group there was a sense of nervousness or embarrassment about

the topic. This could potentially be an area that more participants had concerns about, but due to its delicate or sensitive nature individuals were reluctant to share.

In general, the category or theme of dating, relationships, and potential marriage was clearly a difficult area in many participants' lives. Though the individuals expressed very much wanting to have romantic relationships, many of them found the process daunting or difficult, and some were left questioning if it was even fair to potential partners, and wondered if they would ever successfully find love. The overall tone of the discussions in this area was that participants felt like "damaged goods", which understandably contributes to difficulties in romantic endeavors.

**Kids & fertility.** One theme that was brought up many times in the focus groups was the issue of kids and fertility. The participants discussed that, as cancer survivors, there are some very meaningful ways that this area is different for them than it is for the normal population. First, quite a few of the participants expressed that they were infertile or had reduced fertility and second, aside from fertility issues, being a cancer survivor introduces unique elements into the prospect of having children. These two subcategories and their descriptions are detailed in Table 11.

Table 11  
*Category of “Kids & Fertility”, Subcategories, and Explanations*

Kids & Fertility	Infertility or reduced/compromised fertility	<ul style="list-style-type: none"> <li>• Aggressive cancer treatments affected my ability to reproduce; I am infertile or have a reduced chance of having children biologically</li> <li>• It is a huge and tragic loss</li> <li>• Makes me feel useless</li> <li>• Not being able to have children makes me want them even more; I wish I had the choice</li> </ul>
	Worry over having children	<ul style="list-style-type: none"> <li>• I worry that if I have children my cancer might come back a limit my ability to a good parent, or I might die from cancer and leave my children without a parent</li> <li>• I worry that my children will have cancer too because of a genetic connection</li> </ul>

First, many participants described that due to aggressive treatments they received while in the active phases of cancer, they now are dealing with infertility or reduced fertility. Some described that there is no chance they will be able to biologically reproduce, and others explained that they have dramatically reduced chances of conceiving. While both the men and the women mentioned such concerns, it was clearly the women who expressed more problems and worries about having children. This topic was clearly painful for the participants, and elicited some vulnerable emotions and tearfulness in members of each of the four groups. The survivors stated that other young adults do not have to be concerned with fertility issues and that it was not normal or natural to be barren at such a young age; Lina said, “I can’t have, umm, I am infertile after some of my hardcore treatments, and um, I mean that’s at least one way I’m different than most people my age, they don’t have to think about fertility really. Other

people kind of take those, uh, abilities for granted.” When it came to being infertile or having compromised fertility, individuals described it as a huge loss; they explained that whether or not an individual wants a child, having that choice or option is really important. Furthermore, some individuals mentioned that finding out that they cannot have children only makes them really want children. The survivors expressed grief over their fertility problems, and the female participants mentioned feeling useless as a woman. Lina laments, “It’s not even a chance for me. And you know, as you would expect for a woman, a woman my age, that’s really um, well...”, she trailed off and had to take a moment to compose herself, and went on to say, “it, umm, it’s unfortunate that that’s your um, job as a woman, and I can’t even do that.” Another young woman, Callie, questioned, “Will anyone even want someone who has a useless body”. The survivors exhibited emotional difficulty with this theme in particular, and described feeling as though the one thing that makes a woman a “real woman” was missing in them, which causes them to feel intrinsically flawed. Some reported that such fertility issues can affect or disrupt relationships as well.

Even those that did not report experiencing fertility problems described having different thoughts about kids than “normal” individuals their ages. Survivors explained that having cancer made them very nervous about having children; some expressed worry or concern that they would have a recurrence of cancer and would not be able to adequately parent or worse, would die from cancer and leave their children behind. Others expressed worry that cancer has a genetic component and would perhaps affect their children; Alice stated, “And even, I mean, *should* I have kids, will they have

cancer, ya know? There's the genetic worry. God I couldn't do that to someone... I couldn't handle the guilt." Dave agreed with her and seconded, "Like she said, when you think about if you should have kids or not, you start to think like, will they have cancer?" It was very clear from the focus groups that for young adult cancer survivors, the theme of kids and fertility was very important and very close to their hearts. Some are grieving over the inability to have children biologically, while others who do not report fertility problems still worry about difficulties surrounding having children as a cancer survivor.

**Parents' roles & independence issues.** An area of life that the participants felt was changed by being cancer survivors was that of parental roles and independence issues. The survivors explained that going through the experience of cancer as a child altered the dynamic of their relationships with their parents, and even as young adult survivors they still feel as though they need their parents more than others and are not as independent as their peers, which is a source of stress or frustration for survivors. Issues with parents or independence were broken into four subcategories: (1) very close to or heavily dependent upon parents, (2) parents treat me like a child, (3) not as independent as my friends, and (4) parents' behavior is well-meaning but frustrating. These subcategories are listed and explained in Table 12.

Table 12

Category of “Parents’ Roles & Independence Issues”, Subcategories, and Explanations

Parents’ Roles & Independence Issues	Close to or dependent on my parents	{	<ul style="list-style-type: none"> <li>• I am very close to my parents, I feel like I need them</li> <li>• I live with or near my parents</li> <li>• I rely on my parents for financial resources and support</li> </ul>
	My parents treat me like a child	{	<ul style="list-style-type: none"> <li>• My parents treat me like I am still a child, not like the young adult that I am</li> <li>• My parents are very involved in my daily life</li> <li>• My parents expect to have a say in the decisions I make</li> </ul>
	I am not as independent as my friends or peers	{	<ul style="list-style-type: none"> <li>• I know that most people my age do not have the same level of dependence on their parents</li> <li>• I am much less independent than my peers</li> </ul>
	My parents are well-meaning but I wish I had more freedom	{	<ul style="list-style-type: none"> <li>• I know that my parents’ behaviors are done out of good intentions and love</li> <li>• It is understandable and “makes sense” that my parents are so involved in my life considering my cancer experience</li> <li>• Although I understand why my parents are like this, I find it frustrating and wish things were different</li> <li>• I want to be treated like a normal young adult and have more freedom and independence</li> </ul>

Participants reported that having cancer as a child set a different tone to their relationships with their parents or caregivers; many of them reported that they felt very close to their parents, and still felt like they truly need their parents to be “okay”. Brenda said while laughing, “I still need my mommy” and added, “I still kind of want my mom right there because if something happens I feel like I’ll need her.” Alice described it by saying of her parents, “They’re my security blanket.” Many of the participants explained that as young adult survivors, they are very dependent on their parents. Nine out of the 15 participants reported still living with their parents, and another two described that



although they do not live with their parents they purposefully moved very close to their parents. Most of the participants expressed a continued reliance on their parents financially, whether or not they lived at home.

Participants also reported that their parents treat them more like children than young adults, which they attributed to their cancer experiences. They described that after going through cancer, their parents still perceive them as helpless or needing help and guidance. They described that the whole cancer experience provided an excuse for their parents to keep them as their “kids” and not see them as the young adults they are. Janna stated, “I think most parents never have to really confront the, umm, the likelihood of their kid dying, and so when they do, they’re just different.” The participants explained that their parents are very involved in their daily lives; they described that their parents “have a say on everything” and expect the young adults to “run things by them and get their advice” or “check in with them” before making big decisions. Brenda, a married participant, described, “My mom particularly is probably more involved in my adult life than normal people’s parents, more than she should be probably. She would come and clean and do my laundry and cook for me, she was freaked out and worried that I wasn’t taking care of myself. She’d call me like 4 times a day when she wasn’t there.” Janna described it by saying,

I just, was really close them while I had the cancer. Kind of out of necessity. So when umm, other people were being all rebellious and kind of breaking away from their parents I guess I had to go in the opposite direction and needed them a lot more than ever, and I don’t know, it umm, set the tone for them just having a really big role in my life kind of for good. It’s been hard trying to set up some boundaries for them because, umm, like I said, they still see me as a sick, helpless teenager who really needs them.

Many of the participants had the same experience and described similar scenarios with their parents. Some felt like both they and their parents were guilty; they described that they did not push for setting up boundaries, and in addition their parents rewarded them or gave them attention for being more like a child than an adult.

The participants expressed that there was a clear difference in how they related to their parents compared to their friends and peers; they described not being as independent as their peers, and knowing that it is because they had cancer as children. Ingrid stated, “It’s... way different than how most other people my age get treated by their parents”, and Gabriella added, “I know other people my age who didn’t have to go through all of this, so I think it has something to do with the cancer and them like, wanting to just take care of you, like a kid.” Callie agreed and stated simply, “I’m definitely not as independent as my friends”.

Participants frequently described their parents’ highly involved or overprotective behaviors as “understandable”, “well-meaning”, or as coming out of “good intentions”; may suggested that those types of behaviors “make sense” after having a child with cancer. Janna indicated, “I totally get it. It’s not their fault or anything, I mean, I was really sick and needed them a lot for all of my teen years”. Katelyn added, “But they really have helped me so much that I can’t blame them if they’re a little overprotective. I try to remember that they have gone through a lot too; it was really hard on them... my cancer.” Lina stated, “It kind of makes sense that they’re so, uh, ‘involved’ compared to other people’s parents, us being sick and needing them then kind of set the tone for them feeling like you always need them to take care of you.”

However, even though the participants were able to understand or pardon their parents' over-involved behaviors, they expressed frustration, and mentioned wishing that it was different, or that they had more freedom and independence. Participants frequently used phrases such as "it's frustrating", "it's exhausting", or "it drives me crazy" when talking about their relationships with their parents and lack of independence. Some described that they cannot stand the "smothering" and wished that their parents could see them as grown adults now and treat them accordingly.

Overall, the area of parents' roles and independence was a big concern for the young adult survivors. Many felt like it was a love-hate relationship and a difficult cycle to break; participants described being highly dependent on their parents and relying on them for both resources and support, but they felt as though their parents treated them as children rather than young adults, and this made them feel very different than their peers. They described that though their parents' behaviors were absolutely understandable given the circumstances, they still found it frustrating; they found the relationships "chafing" at times and wished for more freedom and independence.

**Frustration with doctors and health care.** During the focus group interviews, frustration with doctors or health care came up consistently as a concern for young adult cancer survivors. Many of the participants expressed that communication with their health care providers was poor for a variety of reasons, and that even though they know that their doctors and health care teams truly care and want the best for them as patients, their styles of support do not necessarily reflect that all of the time. Participants described feeling as though (1) their doctors and healthcare providers do not provide

them with enough advice, information, and resources, (2) doctors’ interaction styles or methods of obtaining information from participants do not encourage sharing and communication and, (3) even if survivors share their concerns with doctors it will not help. These subcategories are listed and explained in Table 13.

Table 13  
*Category of “Frustration with Doctors & Health Care”, Subcategories, and Explanations*

Frustration with Doctors & HealthCare	Not enough information or advice	<ul style="list-style-type: none"> <li>• My doctors or care providers do not give me enough instructions or information on what I should be doing</li> <li>• No “roadmap”</li> </ul>
	Style not conducive to communication and sharing	<ul style="list-style-type: none"> <li>• I feel like I’m inconveniencing my doctor if I ask questions or want information</li> <li>• My doctors just ask me vague questions that don’t get at how I’m really doing</li> <li>• My doctors expect me to be a “good patient” and not have problems</li> <li>• Health Care workers give me paperwork and questionnaires that aren’t helpful</li> </ul>
	Even if I share my concerns it will not help	<ul style="list-style-type: none"> <li>• I feel like my doctor doesn’t really care about my non-medical problems</li> <li>• If I tell them I am having a tough time they will not do anything about it so it will not help</li> </ul>

First, the survivors expressed frustration at their doctors’ lack of provision of information, instructions, or advice, particularly in regards to what the survivor should actually be doing to “take care” of him or herself. As was mentioned earlier, survivors frequently feel confused or lost as to what they should really be doing to care for themselves in order to maximize health and reduce the chance of recurrence or future disease. They reported feeling like there is no “roadmap” for being a survivor, and they

felt that their doctors or healthcare teams should be the source of this type of information. Alice explained what was needed:

Give it to us straight, tell us exactly what's happening, umm, like what we should be doing to be as okay as we can be, make sure we understand instead of nodding and smiling when we're really just lost and overwhelmed. There should definitely be a roadmap to being a cancer patient, or like 'cancer school', and there should be a roadmap to being a survivor, 'survivor school'.

Second, participants reported that the way in which their doctors interact with them or acquire information about their health or life status does not encourage or facilitate sharing; doctors (a) appear to be inconvenienced by questions, (b) ask vague or unhelpful questions, (c) expect them to be "good patients" and reward them for doing so, and (d) just give me paperwork or questionnaires that are not useful. Participants described that whether intentional or not, their doctors act as though they are inconvenienced by questions or "idle" talk. The survivors explained that to combat feeling lost or confused they want to be able to talk to their doctors for an extended period of time and ask questions during these checkups, but they feel that if they ask questions that are not "yes or no" questions then they are inconveniencing the doctors and taking up too much of their time, and the result is that the survivors try not to ask their providers too many questions or "bother" them.

The survivors described that when they go in for their checkups, their health care teams or doctors ask vague questions that the survivors do not know how to answer; the most common question, according to the survivors, is "Are you doing okay; are you taking care of yourself?" The participants in the groups explained that this is a "one size fits all" question, and it is hard to know how to answer it so they almost exclusively say

“yes, I’m fine” or “I am trying to take care of myself”, and this is not the kind of communication they desire with their doctors. Alice stated, “They don’t ask explicit questions. They just tell you to make sure you’re taking care of yourself and keep coming to your checkups. They ask how you’re doing and like he said, you don’t know what to tell them, because you don’t really know what they want to know, what they mean.” Similar to the theme of “confusion” discussed earlier, it was obvious that the participants did not really know what “okay” meant when doctors asked that question. Participants felt that much like interactions with friends and family, there is a “script” that they are supposed to follow with doctors; doctors expect them to consistently say that they are doing great and moving forward. The survivors expressed that their doctors reward them or give them the most praise or feedback when they mention positive things, like saying that they are doing great or not letting their cancer hold them back; these were noted as hallmarks of being a “good patient”. Because of the “obviousness” of the doctors’ expectations, participants reported just “giving them what they want”, and described that even if they have questions or are experiencing problems, they are not likely to share them with their physicians.

The survivors explained that during ongoing checkups, doctors and healthcare professionals frequently give them paperwork or questionnaires about their status or potential problems. However, the participants feel that such paperwork is not helpful, both because they feel like they know how they are supposed to answer them and they do not believe those questionnaires ever “go anywhere”. It was explained that sometimes the participants are asked to complete a packet of information during their checkups, and

these packets involve surveys that ask about their feelings and overall mood. The participants explained that the aim of such surveys is just to determine whether or not they are suicidal, and unless they are then how they answer will not matter. For example, participants explained that answering in such a way that gives the impression that they are depressed but not suicidal will not warrant attention from their care providers; no one will ever follow up on that paperwork, and therefore how they answer is irrelevant to the type of care they receive. In addition, many participants expressed that the surveys and paper work they are given is transparent; they explained that it is clear they are supposed to answer that they are doing well, and this is especially clear because doctors reward and praise survivors for doing well and being positive. Frida said of paperwork and questionnaires at the doctor's office, "I hate those. You just answer how you're supposed to and get it over with." When asked by the group moderator why she would not share the problems she might be experiencing there, she explained, "I don't know, it just feels stupid, and like no one's going to read it anyway, those just seem like they're trying to make sure you're not thinking about suicide or something, that's all." She went on to say, "I guess they could be helpful in theory, but... you feel stupid if you're saying you have all these problems, that's just not what they want to hear." Alice agreed, adding, "We, or at least I, just zoom through those things, it's obvious how you're supposed to answer" and Brenda continued, "I don't want to say that they wouldn't be helpful, because maybe they could, but not in place of a real conversation" and added, "We never know what happens to those things anyway, it's not like anyone ever tells you how you did or whatever, so they just seem like a lot of pointless paperwork." It was evident that

the survivors felt that their physicians and health care teams could do a better job of communicating and encouraging honest sharing, and that direct and personal conversations would be preferred as a method of obtaining information. The participants added that it would be nice if doctors made them feel like they really cared about the participants by spending more time in the check-up appointments making conversation, really asking about the areas of their lives, and making it clear that it's okay to be having some problems.

Finally, the participants expressed feeling that even if they did happen to share with their health care providers the problems or concerns they experienced, it will not help; nothing will change or be affected. Some of the participants described that it would be pointless to admit to having problems; Edgar summed it up by saying:

[It's] kind of pointless because let's say you do share your problems with him, what's he gonna do about them? Tell you to, umm, hang in there? He's not going to give you actual, actually give you advice and tell you what you need to do. I mean, probably not. Probably he'll give you a wishy washy answer that doesn't help, and then you just feel stupid or like, weak, for coming across like you're having a tough time with there are people out there who are like, dying of it.

It was evident that although participants expressed knowing that doctors care and what them to be at their very best, it is sometimes the case survivors feel like they are not getting what they need from the doctor-patient relationship as a cancer survivor; they expressed a desire to receive more information and advice from their doctors and to have more comfort in communicating with them. Based on participants' experiences, improvement is needed in how health care professionals offer support to and obtain information from survivors. It is important to note, however, that the term "doctors" was



used in a broad sense, and no distinction was made between medical physicians or psychologists and mental health providers. It was unclear from the focus groups whether participants were dissatisfied with the services of the mental health “doctors”, or if they had not been referred to or had seen them at all.

**Recurrence.** Among the concerns or worries that survivors discussed in the group interviews, the possibility of having a recurrence of cancer was noted as one of the most stressful; many identified it as their biggest worry as a survivor. The survivors described that the possibility of recurrence makes it hard to “get over” cancer, because they cannot be sure they will not have cancer again at any time. A third of the participants had already experienced a recurrence and described it as a “devastating experience” and “the most awful feeling”. The mood of anxiety and worry about recurrence was palpable in each of the groups when this theme was discussed. Feelings about potential recurrence were generally described in the following ways: recurrence (1) is my biggest worry, (2) feels inevitable, and (3) requires me to care more about my health.

First, participants described concern over recurrence as their number one worry as a survivor. The survivors explained feeling as though recurrence is a cloud that is always hanging over their heads and consuming their thoughts or worries. Katelyn described that “it’s not something you can escape thinking about”. Individuals mentioned that worry over recurrence is substantial; while survivors are not fazed in the slightest by a runny nose or a sore throat, they get very nervous when they experience any physical symptoms that remind them of cancer. Gabriella explained, “If I have the

flu, I'm like, whatever, big deal.... But other things that feel like it could be the cancer coming back, like if I'm really tired, or have weird pain or something, I start thinking, 'oh no', what if it's back...." Frida agreed, and stated "That's so true! I'm like, ooh a runny nose, big deal! But anything that makes me think of cancer and I'm like, like if I'm tired, I'm all like, greeeaat, this is probably the Leukemia!

According to the participants, this attitude of worry is understandable and just "common sense" as survivors chances of getting cancer again after having it once are substantially higher. This higher likelihood of having a recurrence contributes to survivors feeling like getting cancer again is inevitable. Frida described the feeling by saying, "Like it's just waiting to come out and get me or something, like it's never fully gone, just waiting." She further explained, "I just think it's always going to be there, you know... I don't trust it to stay away." Nicole felt the same way and said, "But I guess you uh, just maybe expect it to happen right, expect that it's going to come back for you at some point." Constantly feeling like the cancer is looming over them and just waiting to attack is a stressful experience for survivors, and one that makes their young adulthood very different than that of their peers. Lina explained the difficulty:

Having that hanging over my head, that there's this awful disease, this one that could kill me, and I've had it twice and I will probably have it again. That sense of um, inevitability about the recurrence, is there, and that's hard. I don't want to feel that way, I want to feel hopeful and optimistic about it staying away, but when you've already had an occurrence it can make you feel... doomed or something.

Survivors explained that considering the high likelihood of a cancer recurrence, they feel like they have to manage their risks as much as possible. They described having to constantly think about whether or not they are minimizing their health risks to

the best of their abilities, and think in terms of long-term health needs as well. This constant need to focus on recurrence and prevention is incredibly difficult for the young adult survivors; they reported feeling that “normal” people do not have to obsess over these things, and this is one more distinction that makes survivors perpetually “abnormal”.

**Physical or body concerns.** Another area that participants identified as being markedly changed by their survivor status was the realm of physical or body concerns. Many participants reported that cancer survivors have different relationships with their bodies than do normal individuals, and this can be evident in a variety of feelings about their bodies: (1) body has failed or cannot be trusted, (2) body is fatigued, (3) appearance and body image are problematic, and (4) an awareness of or an intimacy with body.

These subcategories and explanations are listed in Table 14.

Table 14  
*Category of “Physical or Body Concerns”, Subcategories, and Explanations*

	My body has failed; cannot be trusted	<ul style="list-style-type: none"> <li>• By getting cancer, my body “failed” at its job</li> <li>• It feels like because it failed once, it can and will fail again</li> <li>• I don’t feel like I can trust my own body to stay healthy</li> </ul>
Physical or Body Concerns	My body is fatigued or “put through the ringer”	<ul style="list-style-type: none"> <li>• After going into remission, I still feel fatigued and like my body has been put through the ringer for some time</li> <li>• Feels like I have run a marathon; it takes a while for this feeling to go away</li> </ul>
	My appearance and body image are problematic	<ul style="list-style-type: none"> <li>• Having visible signs or evidence of cancer is stressful for me; they remind me of my cancer and cause others to take notice of me</li> <li>• I try to hide or cover up signs of having cancer in order to feel more “normal”</li> <li>• I don’t feel good about the way I look , and this can cause problems in my</li> </ul>

Table 14 Continued

<p>An awareness of or intimacy with my body</p>	<p>relationships and disrupt my life activities</p>
	<ul style="list-style-type: none"> <li>• I have a clearer or more concrete awareness of my own body whereas others think of their body parts in an abstract way</li> <li>• I feel like I have close “insider knowledge” of my body after having cancer</li> <li>• I feel like my understanding of my own body and its functions makes me appreciative when it “gets it right”</li> </ul>

One recurring theme was the sense from survivors that their bodies had failed them; they described getting cancer as a “failure”, or evidence that their bodies do not measure up in some way. It was described that the ultimate failure of a body is death and as they came close to this, they feel like their bodies have failed them. Gabriella explained, “I don’t know, like, your body failed when it got cancer and almost died on you. If it can fail in that way, if your body’s not good at doing its basic functions... it makes you think like, what else am I not good at.” The word “useless”, among other words that conveyed a sense of failure, was frequently used when people discussed their bodies in the groups. Survivors described an overall sense of distrust toward their bodies as well; Janna stated, “Your body has been bad at things before and you just can’t trust it to do what it’s supposed to do”.

In addition to this sense of failure or inability to rely on or trust their bodies, some survivors described an overall feeling of fatigue that they do not believe is present in most individuals. The survivors described feeling “put through the ringer”, that their bodies are “just tired, more than [they] should be”. Survivors expressed that when they

went into remission, this feeling of fatigue did not lift as quickly as they had expected, and this bodily sense of having run a marathon was strong for some time afterward. However, it was only the participants whose cancer experience was more recent that expressed feeling this way; not all participants noted a continued sense of fatigue.

One of the biggest subcategories discussed under the umbrella of physical or body issues was the survivors' appearance and their feelings about how they look. In relation to body image and appearance, survivors discussed (a) physical signs of cancer and (b) a general sense of unattractiveness or unhappiness with their bodies. The participants reported that as cancer survivors, many of them have what they called "visible signs of cancer" or "evidence", such as scars, amputations, or even minor differences such a slight skin discoloration or area of baldness or thinning hair. The participants described that having such physical differences, however small, can act as constant reminders that they are different than "normal people". One young woman, Brenda, explained that she had a tiny scar on her scalp where hair had not fully grown back; she shared that she uses hair extensions to cover the patch because the thought of anyone seeing that obvious side effect of her cancer was "mortifying". Alice understood Brenda's feelings and added, "... you want to erase visible evidence of the cancer, and scars equal visible evidence." Ingrid, who had a leg amputation as part of her cancer treatment, described that it makes it so she can never forget, even for a day, that she is a cancer survivor. The participants also mentioned that such "visible evidence" of cancer can prompt reactions from people, such as staring or asking questions. The general sense from the participants was that they would prefer to forego those questions and therefore

frequently choose to hide the signs of their cancer, Brenda with her hair extensions as one example, and Ingrid offered another example of not wearing shorts or skirts so that she could hide her prosthesis from strangers. It was clear that having any physical side effects from cancer treatment may serve as another reminder to survivors that “you are not normal”.

Many of the survivors reported an overwhelming dissatisfaction with how they look, especially participants who were women and had physical signs of her cancer experience. Ingrid described feeling very self-conscious about her appearance as a woman and not feeling desired because of her amputation; she stated:

I don't know, I'm happy I got my leg removed because it saved my life and it ended my constant recurrences and gave me some peace from the pain and everything, but, I'm just going to say it... it's not easy feeling sexy or attractive when your body is like this... when you've got this big visible reminder that something's not normal about you. Having a stump for a leg is not very womanly, as you can probably imagine.

Brenda reported feeling similarly about herself due to the scar on her scalp; she explained that having cancer in the past can sometimes make her feel “unwomanly” or “unsexy”, and she explained that covering up the spot or hiding her past cancer experience in general made her feel more normal and “pretty”. Some of the female participants described that feeling badly about their appearances negatively impacts their relationships with others and gets in the way of life activities. Brenda provided the example that each summer she and her husband spend a lot of time with their friends on the lake doing activities like boating, tubing, and jet skiing. She explained that although she would like to join in, she refuses to get in the water because she does not want her hair to get messed up and reveal her scar. She described that this is a source of conflict

between her and her husband each year, and always leads to arguments and tension. Other participants in the group identified with her, and shared that their negative body images had been a source of frustration or problems for them as well.

A rather interesting finding was that aside from having some negative feelings about themselves physically, participants also reported a unique sense of awareness or intimacy with their own bodies. They described having strange but close relationships with their bodies or an expanded understanding of their own bodies and their workings; Ingrid described it being “like you know something that no one else does.” In describing this expanded understanding or concrete awareness of her own body, Janna stated:

You have an, um, different awareness... of your body I guess. Than other people I mean. Like for me... other people think about their body parts and internal, um organs and stuff, abstractly, like they're these magical, unreal, abstract things just hanging out in their bodies doing their thing. Like when other people think of their brain, they think, um, abstractly like about their mind and they don't really think about it... concretely.... I'm like 'So, my brain, someone opened up my skull and cut into my brain, it's right here (points) and when that happens it caused me to have trouble doing some things and so I know that my brain is, real I guess, a *real* thing, that looks a certain way and probably feels a certain way, and is delicate, like can be changed or hurt or damaged or whatever. I don't know if that makes any sense at all, I just have an, umm, more real awareness of my body and body parts I think. It's not abstract for me because someone really did cut into my brain, it's a real thing, a real part, not just some abstract thing you think with.

Ingrid expressed understanding exactly what Janna meant by the feeling of “awareness”, and added:

Like my leg, it's more, umm, concrete than the brain like you're talking about, but still... I feel like when I think of what 'leg' means it's different, um, encompasses more maybe, than what other people think of. I can think of the bones and tendons they had to um, cut through, and what it looks like when it's gone, and just knowing it CAN really be

gone. Most people never have, never um have to have, this level of um, of closeness, with their, their bodies. That's really true. Interesting, right?

The survivors explained that having such a sharp awareness of their own bodies or close relationship to them makes them more appreciative of the complex tasks their bodies perform. While many of them did report feeling as though their bodies had failed them by getting cancer in the first place, they also appreciated their bodies for the things that they do "right". They described a sense of awe about the inner workings of their own bodies, and explained that so many things have to happen inside the body for processes to work according to plan, and that when they do, it feels a little like a miracle, but when they do not, it feels like a terrible let down.

It was evident that survivors have unique relationships with their bodies; they feel as though their bodies have failed them and have been put through the ringer, but also describe a sense of intimacy with or appreciation for their bodies. Many participants discussed a variety of concerns with their physical appearance or being insecure about their looks. It was clear from the discussions that this sense of failure or distrust of their bodies generalizes to their overall feeling about themselves as individuals at times, which is further explored by the following intervening condition.

**Self-esteem & self-efficacy.** Throughout the focus groups, survivors painted a picture of their negative experiences related to having cancer generalizing to how they see themselves or think about their own worth as individuals. Many of the participants expressed that compared to their normal peers their self-beliefs can be more negative or destructive. The survivors described feeling bad about themselves and having poor self-esteem and doubting themselves and feeling like they will not be good at things they try,



and that these problems make them desire external validation or confirmation. The subcategories and explanations of survivors' self-esteem or efficacy concerns are listed in Table 15.

Table 15  
*Category of "Self Esteem & Self Efficacy", Subcategories, and Explanations*

Self Esteem & Self Efficacy	I feel poorly about myself	<ul style="list-style-type: none"> <li>• I feel bad about who I am</li> <li>• I have poor self esteem</li> <li>• Affects my relationships and makes me feel like a failure</li> </ul>
	I doubt my abilities and worth	<ul style="list-style-type: none"> <li>• I don't think I will be good at things or do a good job</li> <li>• I question my worth or if I deserve good things</li> <li>• I feel like getting cancer was a type of failure, and that makes me feel like I will perpetually fail at other things in life</li> </ul>

Group members described feeling bad about themselves more readily than most, and much like having negative feelings about their appearance, experiencing negative self-beliefs can take a toll on their relationships and make them feel like a failure in general. Lina identified feeling bad about herself as a significant way she has been affected by surviving cancer. She explained it as, "Kind of having a lot of um negative... I guess it's just self-esteem. I find myself feeling like, um... just being really critical of myself, of how good I am at things." Nicole agreed with Lina, and explained that after having cancer it "is easy to feel like other things are going to be bad too I think.", and Katelyn further added, "I think she's right... you just feel like um, like things aren't going to be good because you went through this big period of stress where things were

really bad, umm, really hard. It maybe generalizes to feeling bad about yourself in other ways”.

Some participants described doubting themselves or feeling as though they are not deserving of success or good things at times. They described feeling worried that they are not going to be “good enough”, or that they will be “bad at things”; the participants explained that because they “failed” by having cancer and had a very tough time with it, they feel as though they are more likely to fail at other things in life. Edgar described it as “feeling inadequate, like you’re just not going to be up to the job” and like “I’m already doomed to screw something up”. The survivors described that constantly doubting themselves extends to questioning their worth at times; Dave questioned whether or not he would ever deserve his dad being proud of him or be worthy of his girlfriend. Similarly, Brenda wondered if she actually deserved her husband; she questioned, “Should anyone have to be married to a woman who second-guesses herself all the time” and further explained how after her body “failed” those feelings generalized to her sense of worth in general:

I second guess myself all the time. It’s easy to not trust yourself or be sure of yourself. I think after you’ve gone through cancer and it feels like you don’t know or can’t trust your body to do what it’s, well, what it’s supposed to do, and that feeling sort of just generalizes to other parts of yourself. You never know if you can be sure that you’re doing the right thing. I think it’s easier for survivors to not trust ourselves, because, umm to some degree, we’ve proven to be failures in some areas already.

When asked if such self-doubts were unique to cancer survivors, Dave replied:

I mean I’m sure everyone doubts themselves at some point, right? But I think survivors are more likely to feel those ways, because... hmmm, well because when you, I don’t know if this is the right way to explain it but, when go through a big stage of your life feeling helpless, feeling like you

can't do anything to make yourself better, feeling like all of the important decisions are left to other people, it's, it creates the right ingredients for feeling that way later I guess.

It was clear that participants tied their feelings of low self-esteem or self-efficacy to their cancer experiences and survivor statuses. The group members also reported that because of such poor self-assessments, they tend to depend heavily on external validation of their worth; some explained that they seek validation and encouragement from others. It was mentioned that “maybe it's a survivor thing... doubting myself a lot, relying on others for, validation, or confirmation I guess.” Brenda described relying on her husband and her parents to help her make decisions; she explained that because she second-guesses and doubts her own capacity to do well or make good decision, she runs everything by others in her life and cares substantially about their opinions. She added:

My husband wants to strangle me sometimes because I just want, or need, a lot of confirmation before making decisions. I'm really indecisive. Maybe it comes from being a kid with cancer and feeling like all of your decisions about your life are out of your hands, and then turning into a young adult who survived cancer and still having your parents wanting to take care of you and keep an eye on you and be involved in your life.

It was evident that survivors' perceptions are such that they have a tendency to feel bad about themselves easily and experience many self-doubts that cause them to question their worth or ability to make good decisions. Feeling like a failure during the stages of active cancer and feeling as though their bodies failed them generalized to survivors having a compromised sense of self-esteem or self-efficacy.

**Psychological or emotional problems.** The final theme to emerge as an intervening condition in young adult cancer survivorship was psychological or emotional problems. The participants reported that, as survivors, they feel like they experience

more emotional ups and downs, anxiety or worry, depressive symptoms, and trauma-related problems. Some reported taking psychotropic medications to manage the effects of such problems. The subcategories and explanations are listed in Table 16 below.

Table 16  
*Category of “Psychological or Emotional Problems”, Subcategories, and Explanations*

Psychological or Emotional Problems	Emotional ups and downs	<ul style="list-style-type: none"> <li>• After surviving cancer, there are a lot of ups and downs emotionally</li> <li>• It can feel like a rollercoaster</li> <li>• I have to work extra hard to be normal and I’m never quite successful at it, and this creates some uncomfortable emotions</li> </ul>
	Worries and Anxiety	<ul style="list-style-type: none"> <li>• I worry more than normal people do</li> <li>• I have to be concerned about recurrence, my health, future, etc.</li> <li>• I often feel anxious or overwhelmed</li> <li>• Intervention with medication helps to manage my symptoms of anxiety</li> </ul>
	Depression and sadness	<ul style="list-style-type: none"> <li>• I get sad or depressed and feel alone more than most</li> <li>• It’s easy to feel sorry for myself or have a “pity party”, but then I feel guilty</li> <li>• I feel like I am not “allowed” to have problems as a survivor because I no longer have cancer</li> <li>• I can’t share my problems with others because they will think I’m ungrateful or a “brat”</li> </ul>
	Trauma	<ul style="list-style-type: none"> <li>• Surviving cancer is like living through a trauma and can feel like PTSD</li> <li>• Feels like how soldiers experience trauma, but worse in some ways because I can’t truly put my trauma behind me</li> <li>• Cancer treatments contributed to developing medical trauma</li> </ul>

First, group participants expressed experiencing many ups and downs as cancer survivors; Haley described adjustment to life after cancer as “an emotional rollercoaster” with “lots of ups, and lots of downs”. Ingrid agreed and responded, “Like you said, ups

and downs, but then you have to deal with how you feel about the way you feel, and then that can make you feel other ways.... a vicious cycle!” Janna described that how survivors experience their emotions is different than it is for “normal people”, and Nicole added, “I do think that survivors have more emotional and mental stuff to deal with than normal people. We have to work a lot harder to be normal, when that’s something that comes easily for most people.” Survivors explained that the constant strive to be normal is emotionally taxing; they characterized it as particularly difficult because so many things get in the way of normalcy that it is never quite an achievable goal.

Living with uncertainty and the possibility of a cancer recurrence, paired with confusion about how to manage their risks in order to prevent recurrence, contributes to a constant sense of worry or dread; many participants report having problems with anxiety. The participants described worrying more than “the normals” about their health and their futures in general. Owen described that survivors experience more worry and anxiety, but it makes sense to be more anxious when there is a cancer experience in the past:

Survivors, worry more in general, or whatever. But it’s not like we’re hypochondriacs or have some anxiety disorder or something, it’s that when you, um, we just know that some pretty bad things can happen and when they do it can change everything. You know that, um, you can die, and life can be gone in a snap (snaps fingers)... when you feel like you really know those things, it can make you a little, make you have more worries, care more about the things you do and stuff...

Lina agreed, and added that it is hard not to “be freaked out all the time or get crazy about the idea of recurrence and just other stuff too. It’s easy to feel crazy and just, get a

little crazy about it.” Marta also felt like survivors just have so many more things to be nervous or worried about, and expressed that anxiety is legitimate when you have so much “to worry about... relationships, my future career stuff, insurance, how people are around me... lions, tigers, and bears oh my!” It was clear from the focus groups that survivors can experience quite a bit of anxiety, and some of the individuals expressed that their anxiety problems were substantial enough to require intervention with medications. Katelyn stated, “I’ll go ahead and admit that I take anxiety meds for that reason, it just makes me less of a head case, a little calmer, not freaked out”, and Lina responded, “Yeah, I took them for almost 2 years after my last recurrence because it really messed with me, with my emotions and my head.”

In addition to anxiety, some participants reported problems with depression and sadness; Ingrid described that while at times survivors just feel grateful to be alive, other times they feel “Crappy, and bitter. And like no one else can get it, get you, and that can be really lonely. So it’s easy to just get really, blue, I guess, and feel sorry for yourself or have a pity party.” Lina responded, “It’s easy to feel depressed or alone when you’ve gone through something so huge, like cancer”, and Marta added, “I’ve been there too. It kind of comes and goes, those feelings of sadness or being really um, lonely, or pitying yourself.... But that um, depression can just hang over you.” Some participants described the need for medication to manage their feelings of depression or “being down”. Nicole discussed taking medication; she said, “I don’t know if I can blame my cancer or not, but um, it feels like that’s why I have these problems, but um yeah, the pills help me feel better.”

To compound participants' feelings of depression, they also reported feeling guilty for being depressed or having problems, and feel like they cannot share their feelings with others because of it. One participant described it as:

You're sad but you know no one will understand so you're just alone and keep it in, and that's worse. You just are left to like, think about it all the time by yourself. And you know you should get out there and do stuff, but it like, seems overwhelming or even, or pointless sometimes. It's okay to be down and depressed or having trouble when you've got the active cancer and treatment and stuff, but not now, not when you've '*survived*'.

The survivors reported feeling that because they survived and the cancer is gone they are not allowed to be depressed, saying "You don't get to be sad about it because you survived." Ingrid added that when they do happen to start feeling sad or sorry for themselves, they "feel guilty because you're not supposed to feel that way" as a survivor. These feelings of depression and guilt over being depressed as a survivor were cyclical:

You feel depressed, but then you feel guilty about it because you're alive and shouldn't feel that way, and that only makes you feel crappier. Or you see people in even worse situations, like having a harder time with cancer or people who lost somebody and you're like, man, I don't have any right to feel bad.

Survivors described not being able to share these feelings with others because of guilt or "people will think you're really selfish or ungrateful", and therefore often do not seek support or help when feeling down.

In addition to depression and anxiety, each of the four focus groups discussed feeling as though they were suffering through the aftereffects of a trauma, with many individuals comparing it to symptoms of Post-Traumatic Stress Disorder (PTSD).

Katelyn, stated, “It’s like having PTSD, like you survived a big trauma and it’s hard to get over, it haunts you. Like you think about it a lot and can’t get it out of your head, and you’re always nervous it’s coming back, and stuff, uh, just can make you paralyzed with fear. Not literally, but you all know what I mean.” In a separate focus group, Janna likened it to a soldier having PTSD, but explained that it was worse for cancer survivors because the cancer can come back at any time. She stated:

Look, it’s like this, and you girls can jump in and correct me if I’m wrong but, it’s like you have PTSD, like after going to war or something. You’re like a soldier, but like, for soldiers you can leave war and slowly put it behind you and it fades with time... but, with surviving cancer AND having recurrences and just having it come back and knowing it can at any time... I know you’re supposed to get over it, and you’re supposed to move on, and you sort of do, I mean it’s not like every minute of every day I’m shivering in the corner scared that my cancer is going to come back and get me, it’s not like that, but it is like, you’ve got this trauma in your past and, you know, it affects every part of you, and it’s harder to deal with than other kinds of traumas because you, umm, it can realistically come back... you’re not crazy to be scared of that. No one can reassure you and uh say, no, that’s all behind you now, it’s going to be okay, because no one really knows that. So you just really can’t feel safe and just get over it and be normal, there’s always this thing umm, like looming over you. And you have to think of a lot more things than most people do because of it.

In addition to experiencing symptoms of PTSD, the problem of medical trauma was brought up as well. Haley described her experience with medical trauma:

I developed what they call medical trauma, where you get really anxious about any medical tests because of the bad experiences you had with ‘em. Umm, and it, uh made it really hard, like I would cry and, and fight them or just be really nervous or scared about really little things, and umm, even now, I just get really nervous and I have to go through all these relaxation steps every time I get something done. Or I have to take meds. It sucks.



From the focus group interviews it was clear that psychological or emotional problems are big concerns for some participants; individuals described feeling like there are many emotional ups and downs as a survivor, and depression, anxiety, or stress related to trauma can all be problematic for them and require intervention or medication. However, some participants explained that they do not seek the treatment or support they need because they feel guilty about having problems as a survivor; their perception is that after the cancer is in remission they are expected to or supposed to be “okay” and if they admit that they are not okay then everyone will think of them as “ungrateful”, which makes it difficult for survivors to get the help they need.

**Summary of intervening conditions.** All of the intervening conditions that were discussed here emerged as discrete categories or themes in the four focus groups; participants identified these 17 categories as areas that are affected by being a cancer survivor and are meaningful to them as young adults. These areas were often conceptualized by the participants as problematic or as “barriers” to thriving and achieving normalcy. Participants mentioned a variety of strategies or methods that they employ in their attempts to cope with these problems or difficulties; the following section of the model addresses these strategies.

### **Actional/Interactional Strategies**

The cancer survivors reported using different strategies to cope or deal with the above listed problem areas, each with varying degrees of success. Coping methods mentioned by various participants included both cognitive appraisal or emotion-focused

strategies and behaviorally-focused strategies, however, in both styles of approach, avoidance, escape, or ignoring tactics predominated.

Regarding cognitive appraisal or emotion-focused methods, participant strategies included escape-avoidance, accepting the problem or accepting responsibility, distancing, positive reappraisal, focusing on spirituality, and exercising control. The most frequently used appraisal or emotion-focused approach was that of escape or avoidance. Participants admitted to avoiding thinking about things that are scary or worrisome, ignoring their feelings, ignoring working on their perceived problems, hiding any negative feelings, and keeping thoughts to themselves and not sharing with others. Some individuals reported that they cope by just accepting the “badness” of being a survivor or thinking that the worst possible scenario will always happen, that way they do not feel surprised or let down.

Others used distancing techniques to separate themselves from the events or concerns that cause stress; some described asserting to themselves that they are not the sum of their survivorship concerns, and reminding themselves that surviving cancer is not the whole of who they are as people and individuals. Though not frequently used, some participants described using positive reappraisal strategies, such as appreciating being alive and taking joy in the good days or small pleasures in life. Others yet reported relying on spirituality or religion to cope by believing that “things are in God’s hands” or “God has a plan”, and using hope or prayer to reduce stress and anxiety. The final cognitive or emotion-focused strategy that was reported by the participants was exercising control; some individuals described that focusing on the things that are within

their control is one way they cope with the problems or stresses of survivorship.

Participants mentioned that they try to control how they react to others in their lives and focus on having patience; they described that at times they have to remind themselves that other people have been affected by their cancer and deserve patience and understanding too, and this is one thing that is within their control.

Behaviorally-focused strategies for dealing with their concerns and problems as survivors were noted as well; most frequently, avoiding social situations or people or avoiding trying new or difficult things was mentioned as the way that most survivors deal with pressures of survivorship. They also described that behaving according to the expectations of others or “following the script of being a ‘good survivor’” is one way to cope; they just say they are doing fine, smile, act upbeat, and do not ask questions or “rock the boat”. Others mentioned that hiding any visible signs or evidence of cancer, such as scars or amputations is a way of staying under the radar and further avoiding interactions or conversations with others about their survivorship. Some survivors described that keeping very busy or active in their lives can keep survivorship problems from their thoughts; and was considered an effective way to cope. Another behavioral strategy used by some of the survivors was medical intervention; to manage their feelings of anxiety or depressive symptoms participants sought the care of doctors and medication and reported some success with this method. Most of the behavioral strategies mentioned were a type of avoidance or escape employed with the intent to minimize, ignore, or remove themselves from the challenging or uncomfortable aspects of survivorship. However, some individuals reported that positive strategies such as

attending support group meetings, seeking information or resources, and giving back or doing charity work were helpful in managing the stress associating with being a cancer survivor.

In summary, survivors reported using a variety of strategies comprised of both appraisal and emotion-focused and behaviorally-focused approaches to cope with the problems associated with young adult child cancer survivorship; unfortunately, the strategies most often used relied heavily on escape or avoidance. Many participants did not feel that these strategies were serving them well; individuals described that the end result of efforts to manage the survivorship struggle was a young adult who was “surviving rather than thriving”.

### **Consequences**

The consequences section of the grounded theory model describes survivors’ perceived outcomes of their journeys of survivorship. The 17 themes or problems areas that were identified as well as the coping strategies that survivors employ lead to the outcome that group participants described as “surviving rather than thriving”. The survivors reported that overall, they felt “not normal” and very different from their peers regardless of how hard they tried to achieve normalcy. The group participants described that experience with cancer and survivorship had left many of them feeling under-supported and misunderstood, less independent, and behind in life compared to other young adults. Many felt unfulfilled in their home and family lives, social lives, and educational or professional development. Survivors felt that they were not taking the very best care of themselves; specifically, their health or psychological and emotional

needs were not being met, leaving them struggling with confusion and guilt. These outcomes are characterized by survivors feeling victimized by their cancer experience, but feeling as though they cannot share that with others due to expectations of being a “good survivor”. The final result is that participants in the focus groups in this study reported being successful at being a “good survivor” by others’ standards, but not successful at truly thriving by their own standards. However, participants recognized that there are things that could be done to make the process of survivorship better; strategies that could be used to get survivors closer to “thriving” rather than merely “surviving”.

### **Ways to Facilitate Positive Adjustment**

In the process of discussing the themes or concerns that act as barriers to thriving, the survivors identified many strategies they and those around them could employ to “make it better”, that is, to help the survivor feel that they are thriving after their experience with cancer rather than just “making it”. Survivors listed things that they themselves could do, as well as things that friends and family, teachers or bosses, and doctors and health care professionals could do to facilitate positive adjustment to survivorship.

First, survivors made a list of things they could do to help themselves thrive and considered this list to be useful as advice to new survivors as well. The general consensus was that being a better advocate for one’s self and taking an active role in seeking support and resources to meet health, psychological, and emotional needs is the best thing one can do for his or herself as a survivor. The survivors described that one should first be honest with his or herself about what his or her needs and wants truly are,

then do whatever the situation requires to have those needs met. For example, survivors identified making friends and dating as problematic, and suggested that if they were to take more initiative and risks in actively seeking these things out and then being forthcoming about their needs and wants rather than just expecting others to “get it”, then this area would be vastly improved. Survivors further described that they should be more proactive in seeking support and interaction with other survivors, which many of them identified as the best strategy they have used thus far and believed it would be even more beneficial if further sought out. In addition to seeking emotional and social support, the survivors mentioned that increasing their willingness to seek out mental health services when needed could be useful. The survivors also felt that if they focused on having a plan, improving the things in their lives that were within their control or grasp, and improving their positive self-care strategies they would be closer to the goal of “thriving”. They pointed out that it could be helpful to focus on enjoying the small things in life, remembering to be grateful, and giving back to charity or helping others when possible. The survivors seemed to find it particularly valuable to help other survivors who are just starting out their journeys and believed that this would be a good way to “give back”. As a final strategy for facilitating positive adjustment, the participants noted that it is important to not let one’s cancer be who he or she is; to make it a part of one’s story and not his or her whole story. They described that they feel like they are closer to “normal” or “thriving” when their lives are not consumed with the task of “being a cancer survivor”. Lastly, they found it important for survivors to realize that there is no one way to be okay, that each survivor has to find out what works for him or

her. They mentioned that looking at other survivors on television or in the media, such as Lance Armstrong, and feeling like one must do those things to be “thriving” is not helpful and only adds to the pressures and stresses of surviving cancer; the participants noted that each individual should identify what “thriving” really means to them specifically and work on strategies to facilitate that process. It is interesting to note that survivors were able to identify a wide range of adequate coping skills and supports that they “should” be using, however, very little of those techniques were actually reported to be used by the survivors. Seeking mental health services or therapy as a prime example; survivors recognized the utility of such services but were not themselves using them.

Second, survivors listed a variety of things that their friends and family members could do differently to help make things better or easier for the survivor; most of the suggestions the survivors had for others in their lives centered on dropping the script or expectations of what it means to be a “good survivor”, not trying to glorify cancer survivorship, and treating survivors like regular or normal healthy individuals. Survivors described wishing that people around them would understand that the upside of cancer is a myth, and just “admit that cancer sucks, and it’s terrible, and that’s okay”. In that same vein they want people around them to be more “real” and drop the cliché platitudes and inspirational lines; they want others to just be okay with interacting with them as normal people and talking about their cancer experiences in a normal way. The survivors described that neither do they want to be seen as breakable invalids, nor brave and courageous super heroes; they assert that they want to just be treated normally, and that it is okay to have a sense of humor about cancer or talk about it in a direct or honest way.

Additionally, they ask that others please understand that just because the cancer is cured it does not mean that they are automatically better, and sometimes they still need a little extra support for difficulties or concerns. The general advice that participants had for others in their lives was to follow the survivors' leads, try to support them in the ways they need, and understand that those ways may be different than what others might think. Survivors added suggestions specifically meant for parents and caretakers as well; these included: (1) treat me like an adult rather than a child by laying off or micromanaging less, and (2) encourage and facilitate my independence and freedom to the best of your ability.

Third, survivors described certain things that teachers or bosses could do to facilitate their positive adjustment as well. First, survivors stated that their teachers or bosses could be more understanding of their problems or deficits related to having experienced cancer or treatment, most notably, late effects such as cognitive or learning issues. Second, survivors explained that if their teachers or bosses were willing to make accommodations for their unique needs or deficits, then the realms of school and work would be much less stressful or difficult.

Finally, there were things that doctors and health care professionals could do to improve young adult survivors' experiences and facilitate their adjustment. First, survivors expressed a desire for health care professionals to help ease the transition from patient to survivor and facilitate the journey of survivorship by giving more instructions, information, and advice on how best to manage self-care and recurrence risks. Second, the survivors want doctors to take a more active and involved approach to their



interactions with survivors, specifically, participants expressed wanting doctors to spend more time in conversation with them, really checking in and finding out how the survivors are doing in each area of their lives. Also, the participants described that doctors and health care professionals should do a better job at making survivors feel as though it is okay to have questions or concerns and that it is normal to be experiencing problems, and they should do this in a way that makes it clear that they do not feel inconvenienced by the survivors' questions or concerns. The survivors expressed a desire for their doctors to follow through with the questions or concerns the survivors have by offering explicit advice or resources and helping them identify how to deal with their problems. In general, participants desire a more hands-on, caring, and thorough interaction style from their doctors and health care workers; they want to feel as though their needs are thoroughly considered and addressed.

### **Model Summary**

Based on the grounded theory model that was built from the focus group data, it was clear that individuals' unique experiences with cancer was the causal condition, which set into motion a constant pursuit of or quest for normalcy (phenomenon) within the context of balancing the roles of being a cancer survivor with the roles of normal young adulthood. These two roles are conflicting at times; as young adult survivors perceive a certain set of age-appropriate things they "should" be doing, however, being a cancer survivor injects a variety of problems in different areas of their lives and makes them fundamentally different from their peers. Seventeen intervening conditions or

themes were identified by the participants as being affected by their status as cancer survivors, and acting as barriers to being “normal”.

These 17 themes neither operate in a vacuum nor are they static; rather they interrelate and affect one another and can change at different points in a survivor’s journey. One participant named Ingrid who is studying to become a math teacher described all of these “problems” as different elements that are dumped into a funnel, and these elements bounce off of each other and affect one another as they move through this funnel and pipeline to lead to an output or product that is a cancer survivor who feels as though he or she is just “making it” or, surviving rather than thriving.

Although survivors report using some strategies to help mitigate the effects of problems or stressors, most of these strategies rely on maladaptive coping tactics, such as escape or avoidance. It was clear that survivors perceived a variety of ways in which they could be doing a better job to “thrive” rather than “survive” life after cancer. These strategies included things they could be doing, such as being better advocates for their own needs, and things others in their lives, such as friends and family, teachers or bosses, and health care professionals, could be doing. It was understood by the participants that not all survivors feel these same ways, and that some individuals employ great coping tactics that help them to thrive in their lives after cancer, however, individuals in this study described having a hard time with this, and ultimately felt like they were surviving rather than thriving, or were not succeeding in their pursuit of normalcy.

## Integrity of the Data Analysis

In addition to the steps to maintain data integrity that were discussed in Chapter three (member checks, audit trail, etc.), an additional quality check was conducted retrospectively with the data to serve as a sort of “test of fit”. A word frequency analysis was done using NVivo 10; the 25 most frequently used nouns over five characters were identified as well as the five most frequently used adjectives. This is considered a sort of check to determine if the types of words most frequently used by participants are reflected in the grounded theory model and results. The most frequently used nouns and adjectives are listed in Table 17 below:

Table 17  
*NVivo Word Frequency Analysis: Nouns and Adjectives Most Used*

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Nouns	Adjectives
People/Person	Different
Cancer	Normal
Thing/Anything	Little
Survivor(s)	Better
School	Harder
Parents	
Feeling(s)	
Friend(s)	
Problem(s)	
Everyone/Someone/Anyone	
Support	
College	
Health	
Experience(s)	
Insurance	
Doctor(s)	
Thoughts	
Information	
Relationship(s)	
Control	
Recurrence	
Group(s)	
Dating	
Family	
Future	

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Note. Word frequency chose words that were over five characters.

This simple word frequency analysis was done after the data analysis was complete in order to “check” the resulting model. The model is supported as accurately reflecting the raw data when analyses such as these closely match the themes that were ultimately identified in the grounded theory model. The nouns identified in this frequency analysis closely resemble the themes identified as intervening conditions. The adjectives essentially describe the context and central phenomenon of survivorship, with “different” and “normal” being the most used descriptive words, which makes sense as these two competing concepts are the crux of this grounded theory model.

### **Storyline**

In qualitative grounded theory research it can be helpful to construct a hypothetical narrative or storyline that captures the general process and themes of the grounded theory in order to personalize and bring meaning to the model. The following italicized storyline section is a hypothetical first-person narrative that, based on perceptions that arose from the four focus groups, a young adult survivor might report:

*Getting cancer in childhood was an extremely difficult and confusing experience that caused both me and the trajectory of my life to be fundamentally changed. I had to go through intensive treatments, struggled with recurrences, and have been working to get back to being normal ever since. Achieving a sense of normalcy in my life has been a big challenge because I have had to balance trying to be a normal young adult while managing the problems associated with being a cancer survivor. Many areas of my life are different than those of most normal young adults, and each one of these areas contributes to me feeling constantly abnormal or alienated from others.*

*First, I have had to deal with a lot of confusion related to learning how to be a survivor instead of a patient and what that means for me. Although I want to take care of myself in the best ways possible, there is a lot of confusion about how to do that due to conflicting, contradictory, or limited information about self-care and disease prevention. I also feel confused about whether or not I am “okay” or “alright”, because being a survivor skews the meanings of those words for me; I have to ask myself “okay compared to what?” I also feel that as a survivor I’ve had to get used to feeling helpless or out of control of my own life and adjust to having a constant sense of uncertainty or danger in the back of my mind. My overall outlook and attitudes are different than that of my peers; I am more mature in some ways and more immature or behind in others, I have more knowledge about life and how bad things can happen, I am more realistic and less naïve than most people my age, and I have to think about things or prioritize things differently in my life due to my cancer survivorship. Having cancer has also made me intimately aware of my own mortality; I have an acute awareness that my life is short and can end at any moment.*

*Being a cancer survivor has made things like work or school more difficult for me than most; I feel like I am behind other people my age in these areas and that these pursuits are harder due to my being delayed or treatment effects, and in many ways I feel like I have settled for what is easy or doable rather than doing what I really want or pursuing my passion. I feel like having cancer in childhood affected my relationship with my parents; I am more dependent on my parents than others my age, they are very involved in my life on a daily basis, and I do not experience the same level of freedom or*

*independence as others. I understand that my cancer experience was difficult for them too and that their involvement in my life stems from love and good intentions, however, I find it frustrating much of the time and wish I was more like my peers.*

*Interacting with or getting close to others has been difficult as a survivor; I find that others have certain expectations of what it means to be a “good survivor” and these expectations do not really match how I feel. Others expect me to focus on the positives and be optimistic, not complain, be grateful for being alive, and just generally “conquer” my cancer experience. I feel frustrated at times because I feel like this view of survivorship is really a myth, and that in reality there is no bright side or silver lining to experiencing cancer. I look at figures on television like Lance Armstrong and I feel like that’s what people expect of me. I can definitely tell that people reward me for following this script of expectations, so I often behave accordingly, which leaves me feeling unsupported and misunderstood much of the time. This, as well as other problems, really gets in the way of me forming close friendships with others. The area of romantic relationships is problematic as a cancer survivor as well; it’s like I have this big skeleton in my closet that I don’t know how to share with people, and sometimes it’s so hard identifying with others when my collection of experiences is so different than theirs. I sometimes question whether or not I deserve to find love or be happy. To compound relationship difficulties, I also have fertility problems and may not be able to have children due to aggressive cancer treatments. This is a devastating loss for me; it affects my relationships and makes me feel useless.*

*Being a cancer survivor affects me both physically and emotionally or psychologically. In regards to physical or body issues, I feel like having visible signs of cancer make me different than others and act as “evidence” that I’m not normal and cause me to feel bad about my body and how I look. Because my body has failed me in the past, I feel like it is useless and can fail me again, and therefore I do not really trust my body. I do, however, feel a strange intimacy with my body after surviving cancer; I feel like I think of my body and its internal workings in a more concrete sense than others do. In the emotional or psychological realm, I have more problems than most people do. I have lower self-esteem and more self-doubts, I experience more anxiety and depression, and I feel like I have a big trauma in my past that causes me a lot of discomfort. I’ve had to turn to medication to manage my psychological or emotional symptoms. One huge worry that no one else ever has to think about is the possibility of recurrence; because I have had cancer in the past I know I can get it again, and it feels like it is just looming over me and waiting to get me at any time; it is the big boogeyman in my life. It is a constant source of stress but I can’t put it behind me because it’s a realistic possibility.*

*I feel frustrated because I don’t know who to turn to with my problems; my doctors or healthcare providers don’t provide me with enough information or advice and I feel like I am inconveniencing them if I have questions or concerns. I feel most fulfilled when I have the opportunity to interact with other survivors, but there are not very many opportunities for this due to a lack of organized survivor support groups. I*

*felt that as a cancer patient there were many resources available to me, but as a survivor there are not nearly enough.*

*All of these problem areas together can make me feel overwhelmed, and I typically cope with them by avoiding situations that are uncomfortable and ignoring my problems. This hasn't been very effective for me and it leaves me feeling unsupported, confused, overwhelmed, and lonely. Though achieving a sense of normalcy in my life is the most important thing to me, I haven't felt successful at this in most areas. I am left feeling like I am just surviving rather than thriving. I do recognize that this is not the case for everyone and other survivors can be more or less successful at this. I know that there are a variety of ways that things could be better or easier for me; there are things that I could do and things others could do that could facilitate me thriving as a survivor. If I had to pick out one thing that I think is important for everyone to know about my experience as a survivor, it is that this is a battle too; the battle is not over just because I'm in remission.*



## CHAPTER V

### CONCLUSION

In the first chapter, three alternatives were posited for explaining the portrait of normal adjustment that has been painted by most quality of life measures used with the young adult survivor population: (1) young adult survivors truly are functioning adequately compared to healthy controls and do not experience more challenges related to HRQL, (2) the measures that are frequently used are not tapping into the unique concerns and challenges that survivors in this age group may face, or (3) something about the process or method of measurement of psychosocial constructs in young adult survivors precludes the elicitation of the full range of survivors' concerns or problems. The sample of young adults in this study reported a range of difficulties that is greater than would be expected in the general population and, in fact, did so with gusto; a strong mood of frustration and negativity that had not been noted in studies before was noted here. While it may hold true that most survivors demonstrate positive adjustment, it is clear that at least a subgroup, such as that represented in this sample, is struggling significantly and does indeed evidence substantial challenges related to HRQL. Many of the concerns raised by the survivors, such as feeling sexually attractive, worry over marrying, difficulties starting a family, and striving for autonomy, among others, are not represented in quality of life measures developed for children and adolescents, understandably. Additionally, the many dimensions of these specific concerns are underrepresented in measures targeted at the general adult population. It appears that young adults make up a unique developmental group of child cancer survivors who

could benefit from measures targeted directly at the many needs discussed in the focus groups. There have been studies with a related measure, the IOC-CS, which was developed specifically for this age range. This is a measure of impact of disease or illness burden, and looks at how positively or negatively survivors feel they are impacted by their cancer. The eight domains of the IOC-CS (discussed in earlier sections) are all relevant to HRQL and were brought up in the focus groups in some form. The IOC-CS correlates well with existing measures of HRQL and includes some constructs, such as Health Literacy & Personal Growth, that were not previously included in either generic or disease-specific HRQL measures (Zebrack, Donohue, Gurney, Chesler, Bhatia, & Landier, 2010). While there were some topics discussed in the focus groups that are *not* well represented in the IOC-CS (romantic and/or sexual relationships, autonomy or independence issues, insurability concerns, etc.), at this time is the best screener for adjustment problems in this age group. (Zebrack, 2009; Zebrack & Landier, 2011). The third alternative, that something about the common style of HRQL measurement does not “fit” with this group, appeared to hold as well. In prior research there has been a wide range of results regarding survivor functioning, with HRQL measures typically indicating overall normal adjustment, domain rating scales picking up somewhat more concerns in certain areas such as depressive symptoms, somatic complaints, and worries, and interviews and anecdotal caregiver reports revealing yet more general adjustment problems than those indicated on survey measures (Enskar & Bertero, 2010; Hobbie, Stuber, & Meeske, 2000; Kazak et al., 2001; Langeveld, Grootenhuis, VoUte, de Haan, & Van do Bos, 2004, Odo & Potter, 2009; Patenaude & Kupst, 2005). However, even

previous interview research did not elicit the sense of frustration and negativity noted in the focus groups in this study. One previously mentioned study that conducted interviews with young adult survivors noted that participants reported a wide range of troubles; however, in those interviews survivors would counteract those ‘negatives’ with a positive comment, seemingly employing a “compensation” technique. This compensated life picture was not noted in the focus groups. In understanding the negative attitude that predominated in the focus groups and the lack of “making up for it” with compensation techniques, it may be that something about the focus group methodology specifically allowed participants to open up; survivors were able to see other survivors sharing in an environment that closely matched that of a support group, in effect portraying the sense that it was okay to not be okay, leading to an increased willingness to disclose without having to “fix it” by following a negative concern with a positive. In fact, survivors in the focus group specifically remarked on this compensation technique, describing that the focus on a silver lining in survivorship is an expectation or pressure from others, and survivors feel that they must engage in this sort of behavior for the comfort of those around them. In the focus group setting survivors appeared to be free of those pressures as their peers had also experienced cancer survivorship and could therefore “get” them. Furthermore, many of the survivors stated that they are unlikely to share the full scope of their problems in a questionnaire or survey for a variety of reasons. It was clear that something about the focus groups elicited a broader scope of concerns and more openness than has previously been found in studies.

Results from this study hold some meaningful implications for clinical care. Although our health care system is an ever-changing and complicated landscape, it is clear that systemic change is needed in how we evaluate, advocate for, and intervene with young adult survivors of child cancer. There seems to be a large gap that behavioral health services could fill.

Participants were clear that as cancer patients they felt much more supported than they do as survivors. Transitioning to survivorship was like entering uncharted territory. Participants felt like there was no roadmap for being a survivor, and indicated a desire for more information and support from doctors, more support in the realm of skill development and psycho-education, more contact with other survivors, and more understanding from their family members, friends, teachers, and employers.

Survivors lamented not getting what they needed from their doctors; however, participants did not specify whether the term doctors included behavioral health professionals; thus it is unclear what differences may exist across providers. It may be that survivors are either not accessing behavioral health services, or such services are not meeting their needs. Nevertheless, primary care physicians cannot be expected to meet all of the needs of survivors; however, they are excellently situated to act as referral agents to get survivors access to further resources and support, and survivors appear to desire this type of service. It may be helpful for physicians to spend more time with each patient providing psycho-education, answering questions, identifying further support needs, and offering referrals to behavioral health professionals or social workers, who can then address psychosocial concerns or offer information about accessing resources.

In addition to not getting their needs met in the health care system, survivors also expressed unmet community support needs. This concern of not having their information or service needs met was consistent with a recent survey study regarding the amount of unaddressed needs for service or information in recently diagnosed adolescent and young adult survivors (Keegan, Lichtensztajn, Kato, Kent, Wu, West et al., 2012). The authors found that over half of the adolescents and young adults in the study felt that their needs for information were unmet, specifically related to information about cancer recurrence and treatment concerns. Additionally, many of the adolescents and young adults felt that various service and support needs were unmet as well, with a startling 75% expressing needing more support group services.

It was interesting to note in the present study that although participants indicated truly enjoying support groups and interactions with other survivors, they were not actively seeking out or creating these opportunities on their own. This appeared to be a pattern across survivor reports; survivors were able to identify things that could help or make their situations better, but for whatever reason they did not cross that bridge and actually initiate action to get their needs met. Survivors appear to need more assistance, encouragement, and guidance to take the necessary steps to get the services they need, indicating a necessity for a healthcare system that sets them up for success starting from their first follow up appointments after entering remission. It may be necessary for “standard of care” to include a comprehensive needs assessment and provision of psycho-educational information when an individual transitions from active patient to survivor; this care could be initiated by primary care providers and involve consultation

with behavioral health care workers such as psychologists. It is important to identify which survivors could benefit from ongoing intervention and therapy services, especially considering that participants in this study expressed that cancer-specific triggers, such as feeling like one has a “useless body” or “failed at being healthy”, can generalize to infect their overall sense of self-worth and life functioning. Many of the participants reported feeling useless or like failures, experiencing depression, anxiety, and post-traumatic stress symptoms, having trouble with academic and work concerns, and experiencing difficulties in social, familial, and romantic relationships. Considering that the survivors felt that the people in their lives did not support them in the “right” ways and often times made adjustment more difficult, it could be helpful to include family, friends, or significant others in service provision. Many of these problems could be successfully addressed by the inclusion of behavioral health services in standard follow up care. This type of follow up care should include some advocacy training and support, such as that noted in Zebrack, Oeffinger, Hou, and Kaplan (2006). The authors evaluated a four-day retreat program aimed at providing survivors an opportunity to interact with other survivors while learning how to better advocate for themselves, which was found to be very useful.

This study was successful in eliciting a richer picture of concerns than previously was noted, and provides a grounded theory model of understanding the process of young adult survivorship as it relates to quality of life and adjustment. However, further need for research in young adult survivorship is indicated, particularly in the areas of screening for HRQL concerns and developing prevention and intervention programs.

This study supports that young adult survivors are a unique group that express HRQL concerns different from those noted in the child or adolescent measures and general adult measures frequently used, and it is now clear that these measures are not the best choice for young adults. Targeted HRLQ measures appear to be more fitting based on themes that emerged in this study. Scales such as the IOC-CS have the potential to zero in on the areas that are directly meaningful to young adults. Either used in conjunction with broader HRQL measures or alone with further development to include areas of concern identified in this study, such a measure could fit nicely into “standard of care” as a screener in clinical settings. Now that we are beginning to get a better picture of what HRQL concerns this group exhibits, it will be important to conduct further studies in order to better understand the properties and dimensions of these concerns noted here, with the goal of moving toward a comprehensive HRQL measure developed specifically for young adults.

Focus groups appear to be a good fit for eliciting open discourse and gathering information, and seem to elicit a larger number of problems than even other qualitative methods (interviews, open ended questionnaires) have found. However, in moving forward with more focus group research it may be beneficial to employ same-sex focus groups and further restrict the age ranges in future qualitative research endeavors. Sensitive issues such as sexual activity and sexual attraction were constricted to the focus group made up of only women. It may be the case that there are more concerns that were not brought up due to their sensitive or potentially embarrassing natures, and having gender-homogenous focus groups could encourage that type of sharing.

Additionally, the age range utilized was 18-30 years, and it was evident that what was important to those younger individuals at times was not the same as what was valued by the older participants. For example, having children was particularly salient for those at the more mature end of the spectrum, and activities such as going out with friends, drinking, and going on dates was more relevant to those at the younger end of the age range. Future group interview methodologies may find it beneficial to reduce the span of ages in the groups to 5-7 years rather than 13 years. Furthermore, results from this study can be used to aid in the refinement of existing measures. The intervening conditions identified in the grounded theory model may be particularly useful in this regard. A comprehensive HRQL measure that covers the areas specifically important to this developmental group can be a valuable research and clinical tool, and there have been some excellent steps in the right direction in terms of measure development. It is important to note that based on results of this study, young adults may report a wider breadth of concerns when given measures in a conversational interview-style format rather than paper and pencil surveys. Survivors reported not endorsing the extent of their concerns on questionnaires, therefore having a clinician administer a HRQL measure in a conversational tone and non-judgmental environment may be helpful in gathering data on adjustment problems. Aside from these assessment and screening implications, results from this study suggest a need for research toward the development of a standard program of preventative service. One of the focus groups discussed the need for “survivor schools”, or educational programs involving teaching, discussions, and psycho-educational materials (pamphlets, videos, etc.) that would be offered in the



health care setting once patients enter survivorship. Such educational services could provide survivors with the knowledge and support that they feel is missing in their current programs of care. While there have been attempts at developing some rather useful programs geared toward supporting survivors, such as skills-building social retreats and classes, these suggestions have not been widely implemented in practice. Bridging the gap between research and practice is a necessary next step.

The aim of this study was to give young adult survivors a voice in the research in a way that had not yet been done in order to learn about their perceptions of quality of life and what surviving child cancer is like. The experiences and perceptions of survivors in the focus groups revealed a complex grounded theory model of survivorship that centered on pursuing normalcy after experiencing an event that made them fundamentally different, in the context of traversing the already complicated maze of young adulthood. Participants perceived many areas of their lives as fundamentally changed by virtue of being a survivor of childhood cancer, and this particular sample reported struggling with concerns about these areas on a daily basis. The voices were clear—just because a patient goes into remission does not mean the battle with the cancer experience is over. Most research on young adult survivors has determined that the majority of survivors function relatively well in life after cancer and do not exhibit overall adjustment deficits, however, almost all studies put forth the caveat that certain subsets of survivors may exhibit more difficulties. Survivors in this sample appeared to be part of that subset. Higher reports of distress in this sample may be due to characteristics of this specific group of individuals. Participants were recruited from

support group settings, which could indicate that they were seeking support because they were experiencing more problems than the average survivor, or it could be that these particular participants are more likely to share problems or be willing to volunteer for such a study due their support group history. Having a narrow sample from a very particular setting does limit the study's potential for generalizability; however, it gives more information about that subset of survivors about which most studies speculate, those who *do* evidence adjustment concerns. More focus group qualitative research with randomized and varied samples of young adult survivors is needed so that we can determine if survivors from non-support group settings continue to reveal more concerns and adjustment problems when engaged in group interviews. Such results would support that young adult survivors do indeed experience a wide range of concerns related to survivorship that previous methods have failed to capture, and multi-method screening and assessment is needed to identify those survivors who are at risk for such difficulties.

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## APPENDIX A

### WEB ANNOUNCEMENT FOR RECRUITING

## Calling All Survivors!

Are you a young adult (18-30 years) who had cancer as a child or adolescent and survived? You may qualify to take part in a research study being done at Texas A&M University.

Young adult survivors have unique experiences and perceptions, and this research project seeks to learn about YOUR perspectives and experiences in order to **give survivors a voice** in cancer research!

All you have to do to participate is take part in an individual or group interview where you will have the opportunity to discuss your experiences as a cancer survivor.

Interviews are scheduled at your convenience and you will be compensated

**\$25**

If you or someone you know are interested in participating in this study, please contact the Primary Investigator, Stevie Puckett at (832) 382-4109 or [sanctie@neo.tamu.edu](mailto:sanctie@neo.tamu.edu).

## APPENDIX B

### INDIVIDUAL RECRUITING EMAIL

Dear \_\_\_\_\_,

My name is Stevie Puckett and I am contacting you because [“your friend \_\_\_\_\_ indicated that” *or* “your profile on \_\_\_\_\_ indicated that”] you may qualify to take part in a research study at Texas A&M University. Are you a young adult (18-30 years) cancer survivor who was diagnosed before the age of 18?

Young adult survivors have unique experiences and perceptions, and this research project seeks to learn about your perspectives and experiences in order to give survivors a voice in cancer research!

All you have to do to participate is take part in a simple individual or group interview where you will have the opportunity to discuss your unique experiences as a cancer survivor.

Interviews are scheduled at your convenience and you will be compensated \$25 for your time.

If this sounds like something you might be interested in, please contact me and I will be thrilled to provide you with information on how to participate in this research study!

Sincerely,  
Stevie Puckett

**Stevie Puckett**  
**(832) 382-4109**  
[sanctie@neo.tamu.edu](mailto:sanctie@neo.tamu.edu)

**APPENDIX C**  
**INFORMED CONSENT**

**TEXAS A&M UNIVERSITY HUMAN SUBJECTS PROTECTION PROGRAM**  

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**CONSENT FORM**

Project Title: **Quality of Life Concerns in Young Adult Survivors of Child Cancer:  
Developmental Considerations**

**You are being invited to take part in a research study being conducted by Texas A&M University. You are being asked to read this form so that you know about this research study. The information in this form is provided to help you decide whether or not to take part in the research. If you decide to take part in the study, you will be asked to sign this consent form. If you decide you do not want to participate, there will be no penalty to you, and you will not lose any benefit you normally would have.**

**WHY IS THIS STUDY BEING DONE?**

The purpose of this study is to learn about the experiences of young adult cancer survivors, specifically those experiences and perceptions related to their quality of life after surviving childhood cancer.

**WHY AM I BEING ASKED TO BE IN THIS STUDY?**

You are being asked to be in this study because you are a young adult survivor of childhood cancer. For the purposes of this study, this means that you had blood, bone, or tissue cancer before the age of 18 and are now 18 years of age or older and are at least two years post-active treatment for cancer.

**HOW MANY PEOPLE WILL BE ASKED TO BE IN THIS STUDY?**

Overall, between 15 and 40 young adult survivors of childhood cancer will be asked to participate in this study. Most participants are expected to be local (within Texas); however, some participants in other states may potentially be asked to participate in the study.

**WHAT ARE THE ALTERNATIVES TO BEING IN THIS STUDY?**

This study is completely voluntary; the alternative is that you may choose not to participate with no penalty whatsoever.

**WHAT WILL I BE ASKED TO DO IN THIS STUDY?**

If you agree to participate in this study, you will be asked to either take part in an individual interview or a focus group interview. Individual interviews are expected last 30 minutes to 1 hour, and focus group interviews are expected to last 1 ½ to 2 hours. During that time, you will be asked to share your opinions and experiences about what life is like as a survivor of childhood cancer, including how various areas of your life may have been affected by your survivor status. You will also be asked to complete a brief questionnaire that inquires about demographic information so that we can describe characteristics of the individuals who participate, such as average age or average years post-active treatment. You may be contacted after your interview for a few brief follow-up questions.

**WILL VIDEO OR AUDIO RECORDINGS BE MADE OF ME DURING THE STUDY?**

The researchers will audio record the individual or group interview so that they may be transcribed. Please note that all audio recordings will be erased within a length of time not to exceed 4 weeks. Audio recordings will only be listened to by the primary researcher, Stevie Puckett, for the purpose of transcription. Neither tapes nor transcripts will include identifying information; all identifying information is kept locked in a secure location to protect your privacy. If you do not give permission for the audio recording to be obtained, you cannot participate in this study as the recording is necessary for transcription.

**ARE THERE ANY RISKS TO ME?**

The risks of participating in this study are likely to be minimal, but due to the sensitive or personal nature of matters related to surviving cancer, you may encounter some discomfort when thinking about or sharing things that remind you of your experiences. You may refuse to participate, decline to answer any questions, or decide to stop participating at any time, without any penalty. Participation in this research is completely voluntary.

Should you need to talk to a trained professional about issues related to your cancer experience or as a result of discomfort from this interview session, free counseling is available from the CancerCare Helpline at 1-800-813-HOPE (4673).

**ARE THERE ANY BENEFITS TO ME?**

Individuals frequently find participation in such interviews to be rewarding and/or tend to enjoy sharing their experiences with others and hearing the experiences of others (group interviews). Beyond the \$25 thank you bonus and the potential rewarding experience of sharing your perceptions, this research will have no direct benefits for you. However, your contribution of sharing your perceptions and experiences, along with the contributions of other participants, is a valuable part of this research. This project has

been designed to benefit society at large by contributing to the body of knowledge regarding the unique experiences of young adults who survived childhood cancer by learning about those experiences and perceptions first hand from survivors. This research seeks to give a voice to young adult survivors in the scholarly literature, and findings may help inform health care providers, patients, and loved ones about how best to encourage and support high quality of life in survivors.

**WILL THERE BE ANY COSTS TO ME?**

Aside from your time, there are no costs for taking part in the study.

**WILL I BE PAID TO BE IN THIS STUDY?**

You will receive \$25 in cash as a thank you for your participation in the individual or group interview. Disbursement will occur at the end of your interview session.

**WILL INFORMATION FROM THIS STUDY BE KEPT PRIVATE?**

Your individual information will be kept confidential and private. You may use a pseudonym during the interview. The interview will be audio recorded and transcribed. The audio recording will be erased after transcriptions have been completed, thus the interview data you provide will only be stored in a de-identified written format. All digital copies of transcriptions will be stored on a password-protected computer and hard copies will kept in a locked location. Your private information (e.g., name) will not be connected with the transcriptions in any way. Your signed consent form and your contact information will be kept separate from any audio recordings or transcripts. The data collected from this study will be analyzed, presented to other researchers, and written up for publication. Insights that you share, including direct quotations, may be included in the dissemination of this research; however, no personally identifying information of yours will be included with such quotes or excerpts and no one will be able to identify you from this research.

Information about you will be kept confidential to the extent permitted or required by law. People who have access to your information include the Principal Investigator and research study personnel. Representatives of regulatory agencies such as the Office of Human Research Protections (OHRP) and entities such as the Texas A&M University Human Subjects Protection Program may access your records to make sure the study is being run correctly and that information is collected properly.

**WHOM CAN I CONTACT FOR MORE INFORMATION?**

You can call the Principal Investigator to tell him/her about a concern or complaint about this research study. The Principal Investigator Stevie Puckett, B.S. can be called at

(832) 382-4109 or emailed at [sanctie@neo.tamu.edu](mailto:sanctie@neo.tamu.edu). You may also contact the Principal Investigator's advisor, Jan Hughes, Ph.D. at (979) 862-1093 or [jhughes@tamu.edu](mailto:jhughes@tamu.edu).

For questions about your rights as a research participant; or if you have questions, complaints, or concerns about the research and cannot reach the Principal Investigator or want to talk to someone other than the Investigator, you may call the Texas A&M Human Subjects Protection Program office.

- Phone number: (979) 458-4067
- Email: [irb@tamu.edu](mailto:irb@tamu.edu)

### **MAY I CHANGE MY MIND ABOUT PARTICIPATING?**

You have the choice whether or not to be in this research study. You may decide not to participate or stop participating at any time. If you choose not to be in this study, there will be no effect on you in any way. You can stop being in this study at any time with no penalty. Additionally, if the Primary Investigator (Stevie Puckett) believes that participation in the interview is causing you undue distress then the interview will be terminated at no penalty to you.

If new or important information about this study arises that may change your desire or willingness to participate, this will be provided to you in a timely manner.

### **STATEMENT OF CONSENT**

**I agree to be in this study and know that I am not giving up any legal rights by signing this form. The procedures, risks, and benefits have been explained to me, and my questions have been answered. I know that new information about this research study will be provided to me as it becomes available and that the researcher will tell me if I must be removed from the study. I can ask more questions if I want, and may withdraw at any time. A copy of this entire, signed consent form will be given to me.**

---

Participant's Signature

Date

---

Printed Name

Date

### **INVESTIGATOR'S AFFIDAVIT:**

Either I have or my agent has carefully explained to the participant the nature of the above project. I hereby certify that to the best of my knowledge the person who signed

this consent form was informed of the nature, demands, benefits, and risks involved in his/her participation.

---

Signature of Presenter

Date

---

Printed Name

Date

**APPENDIX D**

**PARTICIPANT DEMOGRAPHIC FORM**

Participant Information Form

**Name:** \_\_\_\_\_ **Email (Optional)** \_\_\_\_\_

**Date:** \_\_\_\_\_

**Interview Style (Circle one):**     Focus Group Interview     Individual Interview

**Gender (Circle one):**     Male     Female

**Ethnicity (Circle one):**     White     African American     Hispanic/Latino(a)  
   Asian/Pacific Islander     Other: \_\_\_\_\_

**How old are you now?** \_\_\_\_\_

**How old were you when you were diagnosed with cancer?** \_\_\_\_\_

**What type of Cancer were you diagnosed with?**  
\_\_\_\_\_

**How long have you been in remission/out of active treatment?** \_\_\_\_\_

**What type of treatment did you receive (Examples: targeted proton therapy, chemotherapy, intracranial radiation, surgery, etc.):**  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Are you a student? (Circle one)**     Yes     No  
If yes, describe what your major of study is and what degree you are seeking:  
\_\_\_\_\_

**Are you employed? (Circle one):**     Full Time     Part Time     Not Employed  
If employed, describe your title or the type of job you have:  
\_\_\_\_\_



**What is your current living situation? (Circle one)**

Live Alone

Live with Roommates

Live with Spouse/Partner

Live with Parents or Family

Other \_\_\_\_\_

## APPENDIX E

### WORKING CODES LIST AFTER FOCUS GROUP 1

**Working Coding List** after FG1 was open coded, categories were created, and then back-coded (back translated) using the codes/categories. Some were adjusted and collapsed to go from 37 initial codes down to these 25.

**These will be used to fully code FG2, and will be adjusted, collapsed, and reworked as needed.**

1. Behind in life compared to other young adults
2. Control, Risk Factors, and Self Care
3. Coping and Strategies-- positive or negative
4. Death and Mortality
5. Doctors & Health Care Professionals
6. Expectations of Survivors
7. Feeling victimized, sense of unfairness or unjust
8. How friends and family experience your cancer or survivorship
9. Independence and Parents
10. Kids and Fertility
11. My Outlook or Expectations
12. Myths about survivorship
13. Nobody 'gets it' or understands, only survivors get it
14. Nothing's normal anymore, Everything Changes, Different Path
15. People's Reactions to or interactions with survivors
16. Physical Issues, Body Issues, Body Image
17. Recurrence
18. Romantic Relationships and Marriage
19. School and Work
20. Self Doubts & Self Esteem
21. Survivorship different than being a patient
22. The Cancer Experience
23. Trying to be normal
24. What would help or improve things
25. Worry



*These are the final FG1 25 codes that will be used going forward in coding with FG2.*

## APPENDIX F

### WORKING CODES LIST AFTER FOCUS GROUP 2

Working Coding List after FG2 was coded using the 25 working codes created from the complete FG1 coding/back-coding process.

12 additional codes were created to bring the number from 25 back to 37, however, it is already apparent that some of these are subcategories rather than categories and will be pared down and collapsed as needed later. Some of the 12 codes that were added were not entirely new to FG2, rather they were made clear in FG2 but applied to FG1 as well (i.e., already existed in the data, not newly emerging category but new way of looking at or labeling it).

**\*\*The bolded categories are the ones that were added after the analysis of FG2. The ones that are underlined as well mark the unique contributions of FG2 data (i.e. hadn't been mentioned in FG1).**

1. Behind in life compared to other young adults
2. Being a survivor versus being a patient
3. **Cognitive or Learning Effects**
4. **Confusion about what is 'okay' or 'alright'**
5. **Consequence or outcome**
6. Control, Risk Factors, and Self Care
7. Coping and Strategies-- positive or negative
8. Death and Mortality
9. Doctors & Health Care Professionals
10. Expectations of Survivors
11. Feeling victimized, sense of unfairness or unjust
12. **Financial Concerns**
13. How friends and family experience your cancer or survivorship
14. **Insurability**
15. Kids and Fertility
16. **Lack of organized support for survivors**
17. **Less sympathy for others' problems**
18. **Making Friends, My Social Relationships**
19. **More mature at some things, some things easier for me**
20. My Outlook or Expectations
21. Myths about survivorship
22. Nobody 'gets it' or understands, only survivors get it
23. Nothing's normal anymore, Everything Changes, Different Path

24. Parents' Roles and Independence Issues
25. People's Reactions to or interactions with survivors
26. Physical Issues, Body Issues, Body Image
- 27. Psychological or Emotional Problems**
- 28. Questionnaires**
29. Recurrence
30. Romantic Relationships and Marriage
31. School and Work
32. Self Doubts & Self Esteem
33. The Cancer Experience
34. Trying to be normal
- 35. What people my age 'should' do**
36. What would help or improve things
37. Worry

\*\*Additionally, FG 2 added more information within categories that already existed, but contributed to the subcategories, properties, and dimensions of those categories.

-Priorities change after cancer (Coded under 'Outlook')

-How you deal with death of others around you, not just your own mortality (Coded under 'Death')

-Added lack of trust or faith in body, feeling like it's failed you (Coded under 'Phys and Body')

-First mention of sex, but not distinct category (coded under what people my age should do or feeling behind in life...both of which are aspects of one issue so will likely be combined later)

## APPENDIX G

### WORKING CODES LIST AFTER FOCUS GROUP 3

Working Coding List after FG 3 was coded (using the 37 codes from the ongoing working coding list that was updated after coding FG 2).

**1 additional code was created to bring the number from 37 to 38. FG 3 also added more properties and dimensions to pre-existing codes. This added information will contribute to parsing out subcategories and collapsing and defining categories and relationships in the final steps of analysis.**

**\*\*The new category that was added after the analysis of FG 3 is bolded and underlined.**

1. Behind in life compared to other young adults
2. Being a survivor versus being a patient
3. Cognitive or Learning Effects
4. Confusion about what is 'okay' or 'alright'
5. Consequence or outcome
6. Control, Risk Factors, and Self Care
7. Coping and Strategies-- positive or negative
8. Death and Mortality
9. Doctors & Health Care Professionals
10. Expectations of Survivors
11. Feeling victimized, sense of unfairness or unjust
12. Financial Concerns
13. How friends and family experience your cancer or survivorship
14. Insurability
15. Kids and Fertility
16. Lack of organized support for survivors
17. Less sympathy for others' problems
18. Making Friends, My Social Relationships
19. More mature at some things, some things easier for me
20. My Outlook or Expectations
21. Myths about survivorship
22. Nobody 'gets it' or understands, only survivors get it
23. Nothing's normal anymore, Everything Changes, Different Path
24. Parents' Roles and Independence Issues
25. People's Reactions to or interactions with survivors
26. Physical Issues, Body Issues, Body Image
27. Psychological or Emotional Problems

- 28. Questionnaires
- 29. Recurrence
- 30. Romantic Relationships and Marriage
- 31. School and Work
- 32. Self Doubts & Self Esteem
- 33. The Cancer Experience
- 34. Trying to be normal
- 35. What people my age 'should' do
- 36. What would help or improve things
- 37. Worry
- 38. Sex and Intimacy**

## APPENDIX H

### WORKING CODES LIST AFTER FOCUS GROUP 4

**Working Coding List after FG 4 was coded using the 38 codes from the ongoing working coding list that was updated after the last FG.**

**No additional codes or categories were added. All data fit under previously developed categories. However, FG 4 did contribute more detailed information that aid in understanding and conceptualizing current categories, and all of this information is taken into account during the late stages of analysis when categories are collapsed and subcategories and relationships are defined in the model.**

**The following list of 38 categories is the final iteration of the “Working Codes List”, and the next step is collapse and edit these categories into a FINAL list that will be used to define a model.**

1. Behind in life compared to other young adults
2. Being a survivor versus being a patient
3. Cognitive or Learning Effects
4. Confusion about what is 'okay' or 'alright'
5. Consequence or outcome
6. Control, Risk Factors, and Self Care
7. Coping and Strategies-- positive or negative
8. Death and Mortality
9. Doctors & Health Care Professionals
10. Expectations of Survivors
11. Feeling victimized, sense of unfairness or unjust
12. Financial Concerns
13. How friends and family experience your cancer or survivorship
14. Insurability
15. Kids and Fertility
16. Lack of organized support for survivors
17. Less sympathy for others' problems
18. Making Friends, My Social Relationships
19. More mature at some things, some things easier for me
20. My Outlook or Expectations
21. Myths about survivorship
22. Nobody 'gets it' or understands, only survivors get it
23. Nothing's normal anymore, Everything Changes, Different Path
24. Parents' Roles and Independence Issues

25. People's Reactions to or interactions with survivors
26. Physical Issues, Body Issues, Body Image
27. Psychological or Emotional Problems
28. Questionnaires
29. Recurrence
30. Romantic Relationships and Marriage
31. School and Work
32. Self Doubts & Self Esteem
33. The Cancer Experience
34. Trying to be normal
35. What people my age 'should' do
36. What would help or improve things
37. Worry
38. Sex and Intimacy



## APPENDIX I

### FINAL LIST OF CATEGORIES AND SUBCATEGORIES OF GROUNDED THEORY MODEL

**Causal Condition=**

The Cancer Experience

**Phenomenon=**

The Pursuit of Normalcy:

**Context=** Within the context of being both a young adult, which has its own roles and responsibilities, and a cancer survivor, which is often in direct opposition to parts of being a normal young adult.

What people my age SHOULD be doing (i.e. what is 'normal'?)

Cancer changes everything, Nothing is normal

**Intervening Conditions=** (or, What gets in the way of my being normal, what is affected by being a cancer survivor?)

1) Confusion

- Being a survivor vs being a patient
- What is "okay"? Am I "okay" or "alright"?
- Confusion about how to take care of myself

2) Feeling out of control

- Feeling helpless or powerless
- Feel like it's hard to know what to try to control versus what to accept

3) School

- Late start or feeling behind
- Dropped out or didn't go to school
- Not liking school or takes too long
- Cognitive or Learning Late Effects make school hard
- Not doing what I really want

4) Work & Financial Concerns

- Getting a job, getting hired
- Not doing what I really want
- Insurability
- Financial Concerns

5) My Outlook, Attitudes, and Expectations

- Always feeling unsafe or in danger or having sense of uncertainty
- More mature in some ways, I don't sweat the small stuff
- Expectations or knowledge
  - i. More realistic, less naïve
  - ii. Expect bad things to happen
  - iii. More knowledge of life than most
  - iv. I have to think about things differently
- Priorities change
- Sense of own mortality, handle death differently

6) The Myth of survivorship

7) Expectations of Survivors, script for being a “Good Survivor”

8) Social Life & Interactions

- How friends and family experience your cancer or survivorship
- People's reactions to or interactions with survivors
- Making friends, connecting with others
- Less sympathy for others' problems
- Only other survivors seem to “get it”

9) Romantic Relationships and Marriage

- Wanting to date, feeling lonely
- Relationships are a big commitment/responsibility
- Feel behind or inexperienced
- Hard to date, hard to share (Hard to share self, difficult conversations, hard to meet, etc.)
- Will I find love or even should I? Is it fair to a partner (fertility issues, recurrence possibilities, emotional baggage)
- Sex and Intimacy

10) Kids and Fertility

- Infertility or reduced/compromised fertility (treatment caused fertility problems, tragic loss, makes me feel useless or broken)
- Worry over having children (will they have cancer, will I get cancer again and be a subpar parent, etc.)

11) Self Esteem and Self Efficacy

- Feel bad about myself very easily
- I doubt myself or second guess myself a lot

12) Psychological or Emotional Problems

- A lot of emotional ups and downs

- Anxiety and worry
- Depression and sadness
- Trauma

13) Parents' Roles and Independence Issues

- Close to or dependent on parents
- Treat me like a child, not like an adult
- I am not as independent as peers
- Parents mean well but it's frustrating to me, I wish I had more freedom

14) Doctors & Health Care

- Don't provide enough information, instructions, or advice
- Style not conducive to communicating or sharing
  - I feel like I am inconveniencing them
  - I know they care, but their behavior doesn't reflect it sometimes
  - Expectation for you to be a good patient
  - They just ask me vague questions that I don't know how to answer
  - Give me questionnaires and paperwork that I don't think are useful
- Even if I share my concerns it will not help

15) Lack of Organized Support for Survivors

16) Recurrence

- Biggest worry of a survivor
- Feels inevitable, always expect it to come back
- I have to care more about taking care of my health to reduce risk of recurrence

17) Physical or Body Concerns

- Feel like my body has failed me, can't be trusted, useless
- Feel fatigued at times, like body's been put through the ringer
- My body image and how I look/physical evidence of cancer
- An awareness of or intimacy with my own body

**Actional/Interactional Strategies=**

Coping and Strategies

a. Appraisal or Emotionally-Focused Strategies

- Escape-avoidance
- Accepting the problem or responsibility
- Distancing
- Positive Reappraisal

- Spirituality
- Exercising control
- b. Behaviorally-Focused Strategies
  - Avoiding social situations or people, avoiding trying new or difficult things
  - Following along with expectations of others
  - Hiding visible signs of cancer
  - Keeping busy or active
  - Medical intervention
  - Attending support group meetings
  - Seeking information or resources
  - Doing charity work

### **Consequences=**

Consequences and Outcomes: Described as “Surviving rather than thriving”

- Not normal, very different from peers
- Under-supported, needs not being met (social, psychological, emotional, health)
- Less independent
- Behind in lives
- Unfulfilled in regards to friendships, romantic relationships, and parental relationships
- Dissatisfied in educational or career development
- Confusion and guilt
- Feel like they can't share with others
- Feel like I'm settling
- Feel pressured

### **Ways to Facilitate Adaptive Adjustment=**

What helps to make it better, or what would help to make it better?

- a. What friends and family can do
  - Admit that 'cancer sucks, and it's terrible, and that's okay
  - Be more 'real', less cheesy platitudes and inspirational lines, media, and movies, etc.
  - Be okay with talking about my cancer
  - Don't treat me like a superhero, or brave, or courageous unless I've truly done something to warrant it
  - Have a sense of humor, it's okay to laugh with us
  - Know that I am not breakable or an invalid because I had cancer
  - Put less pressure on us to the 'good survivor'
  - Treat me like a normal person

- Try to support me in the ways I need, understand it might not be what you think I need
  - Understand that just because the cancer is cured, doesn't mean I'm better
  - Understand that the 'upside' of cancer is a myth
- b. What my parents can do
- Treat me like an adult instead of a child
  - 'Lay off', micromanage less
  - Encourage me to be independent
- c. What health professionals can do
- Give me more instructions, info, and advice on how to take care of myself, prevent recurrence, etc.
  - Make me feel like it's okay to have questions, it's normal to be experiencing problems, etc.
  - More indepth, involved approach to finding out how I'm doing
  - Talk to me more, really check in with me
- d. What I can do
- Work harder to make friends and be social
  - Work harder at being independent
  - Try to tell people what I need from them, how they can help me rather than expect them to just know
  - Take more initiative and risks with dating and finding partner
  - Seek support from other survivors
  - Realize that there's no one way to be okay, you have to find what works for you
  - Give back, charity, use my body for 'good'
  - Get counseling if I need it, seek out mental health help
  - Focus on positive self-care
  - Focus on having a plan, control the things I can
  - Enjoy the small things
  - Don't let your cancer be who you are, make it part of your story not your whole story
  - Be a better advocate for myself and take more ownership and responsibility of my needs
- e. What my teachers or bosses can do
- Be understanding about my problems or deficits
  - Accommodations for my needs