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**Social Functioning Among Young Adult Cancer Survivors Upon Transition from Active Treatment to Survivorship Care**

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**Social Functioning Among Young Adult Cancer Survivors Upon Transition from  
Active Treatment to Survivorship Care**

**by**

**Casey Anne Walsh**

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# **Social Functioning Among Young Adult Cancer Survivors Upon Transition from Active Treatment to Survivorship Care**

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The University of Texas at Austin, 2018

Supervisor: Barbara Jones

During the transition process from active treatment to survivorship care young adult cancer survivors are facing the opportunities and challenges of social reintegration as they manage ongoing treatment effects. This study explores the social functioning of young adult cancer survivors during this critical transition process. Qualitative interviews were conducted with study participants ( $N=13$ ; ages 17-25 at the time of cancer diagnosis) within approximately 6 months of the completion of active treatment and 3 months later. Participants completed supplemental self-report measures of social functioning at both time points.

Applied thematic analysis was used to identify themes from participant interviews. Six key themes and twelve sub-themes emerged regarding participant interactions with their support system (“Being there”, “Staying strong”, & “Treat me the same”) and healthcare team (“Connection and relationship building” & “Seeking knowledge and engaging in advocacy”), as well as treatment effects (“Uncertainty, Loss, & Changes in Identity” & “Ups & Downs of Physical Symptoms”), coping strategies (“Keep busy” & “Keep a positive vibe”), support resources (“Support needs change over time”), and post-treatment experiences (“Trying new things to cope with losses” and “Managing expectations with realities”).

On the supplemental self-report measures of social functioning, three participants (25% of the study sample ( $n=12$ ) who completed questionnaires at both time points) experienced mild or moderate impairment in multiple domains of social functioning. There were no statistically significant differences between groups in participant T-scores at Time One and Time Two on any of the measures.

Study participants often experienced reduced self-efficacy for managing social interactions during the transition from active treatment to survivorship care. Study participants who experienced more severe physical treatment effects, who had unaddressed mental health needs, and who were younger at the time of cancer diagnosis experienced more impairment in social functioning post-treatment. Findings from this study support screening for the social functioning of AYAs early and often in the care trajectory to identify patients who may need additional support and to provide referrals to age-appropriate resources as needed. Opportunities for AYAs to stay involved socially and professionally should be fostered throughout treatment and beyond.

## Table of Contents

List of Tables .....	x
List of Figures .....	xi
Chapter 1 Study Background & Significance.....	1
Introduction.....	1
Key Terms & Concepts.....	1
Emergence of AYA Oncology.....	5
Unique Needs of AYAs .....	9
Problem Statement.....	10
Study Aims.....	10
Research Questions .....	11
Study Significance .....	11
Chapter 2 Theories & Conceptual Models.....	12
Introduction.....	12
The Theory of Emerging Adulthood.....	12
The Transactional Model .....	14
Optimal Matching Model of Stress & Social Support.....	17
Social Ecological Framework .....	18
Chapter Summary .....	19
Chapter 3 Literature Review .....	21
Introduction.....	21
Overview of Search Strategy & Study Selection.....	21
Review of Findings .....	22
Implications.....	27
Chapter 4 Methodology .....	31
Introduction.....	31
Study Design.....	31
Study Sample .....	33



Study Measures .....	37
Interview Guides .....	37
Self-Report Measures.....	38
Data Management & Analysis .....	40
Qualitative Analysis.....	40
Strategies to Enhance Rigor.....	42
Quantitative Analysis.....	42
Chapter 5: Qualitative Findings .....	44
Introduction.....	44
Key Themes .....	45
Discussion .....	70
Chapter 6: Quantitative Findings .....	73
Introduction.....	73
Time 1 .....	73
Time 2 .....	74
Comparison of T-Scores Between Time 1 & Time 2 .....	77
Discussion .....	82
Chapter 7: Discussion .....	83
Introduction.....	83
Integration of Findings.....	83
Study Strengths & Limitations.....	89
Chapter 8: Implications.....	91
Introduction.....	91
Clinical Implications.....	91
Research Implications .....	94
Policy Implications .....	95
Conclusions.....	97

<b>APPENDICES .....</b>	<b>105</b>
Appendix A Code Frequencies & Co-Occurrences Table.....	105
Appendix B Member Checking Feedback.....	106
Appendix C Sociodemographic Questionnaire.....	108
Appendix D Interview Guide.....	110
Appendix E Member Checking Form.....	111
Bibliography .....	112

## List of Tables

Table 1: Literature Review .....	28
Table 2: Participant Sociodemographics .....	35
Table 3: Key Themes & Sub-Themes.....	45
Table 4: Scale Descriptives.....	76

## **List of Figures**

Figure 1: Study Flow .....	33
Figure 2: Participation in Social Roles & Activities.....	78
Figure 3: Satisfaction with Social Roles & Activities .....	79
Figure 4: Self-Efficacy for Managing Social Interactions.....	80
Figure 5: Social Isolation .....	81

## **Chapter 1: Study Background & Significance**

### **Introduction**

This chapter will begin with a review of the key terms and concepts relevant in the study of the social functioning of young adult cancer survivors. The emergence of the field of adolescent and young adult (AYA) oncology in the United States will be discussed to provide context for the ongoing development of specialized clinical and research efforts. The unique medical and psychosocial needs of AYAs will be reviewed. The key components of this study including the problem statement, study aims, research questions, and study significance will be provided.

**Key Terms & Concepts.** Each year, approximately 70,000 adolescents and young adults (ages 15-39) are diagnosed with cancer in the United States (National Cancer Institute, 2015). Cancer is the most common cause of death among individuals ages 15 through 39 years old after homicides, suicides, and unintentional injuries (Bleyer & Barr, 2009). The majority of cases of cancer occurring before age 30 appear to be spontaneous and unrelated to either carcinogens in the environment or family cancer syndromes (Bleyer, O'Leary, Barr, & Ries, 2006). However, there are clear targets for AYA cancer prevention, such as limiting solar exposure (Lower, Girgis, & Samson-Fisher, 1998), promotion of vaccines for human papillomavirus (HPV) and hepatitis (Barr, 2011), prevention of tobacco use (Tomar, Winn, Swango, Giovino, & Kleinman, 1997), and access to routine cervical cancer screening for all sexually active female adolescents (Mangan et al., 1997). The incidence of specific cancer types varies according to age (National Cancer Institute, 2015). Among 15-24 year olds, the most common cancers are leukemia, lymphoma, testicular cancer, and thyroid cancer (National Cancer Institute, 2015). Among 25-39 year olds, the most common cancers are breast cancer and melanoma (National Cancer Institute, 2015).

Incidence rates of cancers among AYAs vary by race and ethnicity (Bleyer, O’Leary, Barr, & Ries, 2006). Non-Hispanic whites have the highest risk of developing cancer during this phase of life, while Asians, American Indians, and Alaskan Natives have the lowest risk (Bleyer, O’Leary, Barr, & Ries, 2006). In terms of prognosis, males have a worse prognosis than females (Bleyer, O’Leary, Barr, & Ries, 2006). Additionally, African Americans/blacks and American Indian/Alaska Natives have a worse prognosis than non-Hispanic whites and Asians (Bleyer, O’Leary, Barr, & Ries, 2006). Among 15- to 29-year olds, non-Hispanic whites have the best survival rates and African Americans/blacks have the worst survival rates, with a stark 20% difference apparent by 5 years (Bleyer, O’Leary, Barr, & Ries, 2006). Asians/Pacific Islanders have the second best survival rates, followed by Hispanics and American Indians/Alaska Natives (Bleyer, O’Leary, Barr, & Ries, 2006). Racial and ethnic disparities in cancer survival rates suggest inequities in timely diagnosis, accessible and appropriate treatment, and supportive care services (Block, 2015).

There are differing definitions of the AYA age range across the field nationally and internationally. In 2006, the National Cancer Institute, with support from the LIVESTRONG Foundation, held a Progress Review Group to examine the state of the science for AYAs with cancer diagnosed between 15 and 39 years of age (National Cancer Institute, 2006). A key initial decision of the workshop was defining the AYA age range. With a desire to enable comparison to previous studies and to foster continued monitoring of this vulnerable population, attendees agreed to recommend continued use of the Progress Review Group definition for AYAs: ages 15-39 at diagnosis (National Cancer Institute, 2006). They recommended that future AYA oncology research studies should include a rationale for the ages chosen and should flexibly apply the age range based upon the research questions being examined, such as biology based for epidemiologic studies and

developmentally based definitions for psychosocial research (National Cancer Institute, 2006). The Surveillance Epidemiology and End Results (SEER) Program had previously set the upper age limit at 29 years old for epidemiology in the United States, and the Canadian Cancer Society and Statistics Canada also use this age range (Barr, Ferrari, Ries, Whelan & Bleyer, 2016). In Europe, the upper age has been set at 24 by the **European Cancer Registry** (Eurocare) based study on survival and care of cancer patients (Gatta, Capocaccia, De Angelis, Stiller, & Coebergh, 2003). In Australia, the AYA age range is 15-29 (Australian Institute of Health and Welfare, 2011).

Clinically, varying age distinctions have implications for psychosocial programming, provider expertise, research efforts, and resource needs in AYA cancer care programs (Barr, 2011). Even within the AYA age range, there is a huge range of developmental and psychosocial needs. Additionally, AYA is sometimes used to refer to AYA survivors that may include those diagnosed as children under age 15, as well as those diagnosed between ages 15-39. In this study, as informed by the Theory of Emerging Adulthood (Arnett, 2000), individuals diagnosed with cancer between the ages of 18-25 have been included. In terms of research efforts, the variance in age-group definitions creates challenges with pooling aggregate data and limits AYA-specific meta-analyses (Lang, David & Giese-Davis, 2015). When there is a lack of clarity about the patient population, this also impacts the generalizability and practical application of findings. Additionally, research studies rarely reported using developmental theories to guide their age categorization, with few studies giving any rationale for their age-group definitions (Lang, David, & Giese-Davis, 2015).

Over time, the meaning of “cancer survivor” has evolved. When cancer was considered incurable, the term ‘survivor’ referred to the caregivers and family members who had lost a loved one to cancer (Leigh, 1996). As treatments have advanced, survivor

referred to individuals who remained cancer-free for a minimum of five years (Twombly, 2004). Survivorship has also been considered a distinct phase in the cancer trajectory that occurs between the end of primary treatment and recurrence or end of life (Rowland, 2007). Currently, the National Coalition for Cancer Survivorship (NCCS) defines survivorship as beginning at the time of diagnosis and continuing for the balance of life, in living with, through, and beyond a cancer diagnosis (NCCS, 1995-2016). This study focuses on the specific period of survivorship care provided upon completion of active treatment. Transition issues that should be addressed with AYA cancer survivors include physical health and function, sexual/reproductive health, mental health, social competence, health education, and health behaviors (Nathan, Hayes-Lattin, Sisler, & Hudson, 2011). Transition services should be available to AYAs throughout the survivorship spectrum (Freyer, 2010). The availability of resources for survivors varies by survivor characteristics, healthcare system, and geographic location (Nathan, Hayes-Lattin, Sisler, & Hudson, 2011).

AYAs experience multiple transitions throughout their cancer journey, from health to diagnosis of a life-threatening condition, from diagnosis to treatment, and from treatment to survivorship or palliation (Nathan, Hayes-Lattin, Sisler, & Hudson, 2011). For AYAs, these transitions are occurring during a developmental phase characterized by exploration and identity development (Arnett, 2000). AYAs transitioning into follow-up care identify concerns related to finishing treatment, ongoing health concerns, and future life directions (Thompson, Palmer, & Dyson, 2009). AYAs unmet psychosocial needs appear to vary across the continuum of care and to be related to the developmental priorities of emerging adulthood (Millar, Patterson, & Desille, 2010; Arnett, 2000). AYAs need a time-sensitive and ongoing approach for monitoring their psychosocial needs and providing psychosocial services across the cancer care trajectory (Millar, Patterson, & Desille, 2010).



Understanding AYAs' social support needs is critically important in designing and maintaining effective AYA psychosocial programming (Kent et al., 2013). Individuals may draw upon social support from various sources including family and friends, other cancer survivors, and their healthcare team. Recent research suggests that AYA cancer survivors have a lower level of perceived social support provided by family, friends, and significant others than their healthy peers (Tremolada, Bonichini, Basso, & Pillon, 2016). Risk factors identified for poorer health-related quality of life and social functioning include female gender, the diagnosis of hematological disorder, hematopoietic stem cell transplantation, and a shorter off-treatment period (Tremolada, Bonichini, Basso, & Pillon, 2016). Various types of support, including emotional support, network support, esteem support, tangible aid, and informational support may be needed at different times in the care trajectory depending upon the stressors at that time (Cutrona & Russell, 1990).

**Emergence of AYA Oncology.** Historically, AYAs have been caught between the worlds of pediatric and adult oncology (Ferrari et al., 2010). AYAs with cancer have faced slower rates of improvement in survival (compared with younger and older age groups), low accrual to clinical trials, and disparities in health and psychosocial outcomes (Freyer, Felgenhauer, & Perentesis, 2013). The percentage of AYAs enrolled into cancer clinical trials is significantly lower compared with children aged <15 years (Bleyer, 2002). Young adults in the United States ages 26 to 34 are more likely to be uninsured than any other age group (Barnett & Berchick, 2017). Recent results from the Adolescent and Young Adult Health Outcomes and Patient Experience (AYA HOPE) study reported that 25% of cancer survivors were without health insurance at some time in the first 35 months after their diagnosis (Parsons et al., 2014). Uninsured AYA cancer survivors report reduced health care access and a higher risk of forgoing medical care due to costs compared with insured survivors (Kirchhoff, Lyles, Fluchel, Wright, & Leisenring, 2012). While cancer remains

the most common cause of disease-related death among AYAs in high-income countries, their overall survival rates are beginning to increase due to advancements in supportive care and active treatment (Barr, Ferrari, Ries, Whelan, & Bleyer, 2016). AYA focused initiatives within the National Clinical Trials Network are working to improve accrual of AYA cancer patients onto clinical trials (Weiss et al., 2015).

The field of AYA oncology has emerged through the collective advocacy efforts of survivors, clinicians, advocates, and researchers to help improve the health and psychosocial outcomes of AYAs facing cancer. AYA oncology is described as a specialty in its late adolescence, as advances in clinical care and research have emerged over the past decade (Shaw et al., 2015). In 2006, the Progress Review Group, a collaboration between the U.S. National Cancer Institute and the LiveSTRONG Foundation, convened to make executive recommendations about awareness, education, research, prevention, diagnosis, treatment, and quality of life and to address psychosocial issues AYA oncology patients face (National Cancer Institute, 2006). In 2013, the Children's Oncology Group published a blueprint for research in AYA oncology, emphasizing the need for collaboration between the Children's Oncology Group and the National Cancer Institute funded adult cooperative groups to utilize their complementary strengths to advance clinical trials across pediatric and adult cooperative groups (Freyer, Felgenhauer, & Perentesis, 2013). In 2006, the LIVESTRONG Young Adult Alliance, co-sponsored by the Lance Armstrong Foundation and the National Cancer Institute, was developed as a vehicle for a strategic plan designed to implement the Adolescent and Young Adult Oncology Progress Review Group recommendations (Mathews-Bradshaw, Johnson, Kaplan, Craddock, & Hayes-Lattin, 2011). In 2011, with the successful conclusion of the Progress Review Group's 5-year implementation plan, the Alliance transitioned from a program of the Lance Armstrong Foundation into an independent non-profit organization for AYA oncology professionals

called Critical Mass: The Young Adult Cancer Alliance (Johnson, 2013). Critical Mass: The Young Adult Cancer Alliance represents the AYA cancer community, identifies barriers facing AYAs with cancer, and works with policy makers to overcome them (Critical Mass, 2018).

In the United States, the lack of a national health insurance program creates challenges with broad scale AYA program implementation (Shaw et al., 2015). AYA cancer care in the United States is delivered across a broad range of healthcare settings, including academic institutions, National Cancer Institute designated cancer centers, free-standing community cancer programs, ambulatory care clinics (such as radiation clinics and chemotherapy infusion units), individual practices, and pediatric and medical oncology groups (Zebrack, Mathews-Bradshaw, & Siegel, 2010). AYAs are the least likely of all age groups to be treated at comprehensive cancer centers (Isenalumhe, Fridgen, Beaupin, Quinn, & Reed, 2016). A lower likelihood of treatment at NCI-designated Comprehensive Cancer Centers (NCICCC) has been associated with African American or Hispanic race/ethnicity, lack of private insurance, less than high SES, and living farther than 9 miles away from the nearest NCICCC (Wolfson, Sun, Wyatt, Hurria, & Bhatia, 2015).

Pediatric oncology care is often centralized at major academic medical centers, while adult medical oncology care is more commonly provided in community private practice settings by individual oncologists who refer to specialists as needed (Ferrari et al., 2010). There is growing awareness of the need for integrated strategies that allow young adults to benefit from the combined expertise of pediatric and adult oncologists in systems that identify both the complex disease and psychosocial issues specific to this population (Bleyer, Barr, Ries, Whelan & Ferrari, 2016). Understanding the biological, psychological, and social contexts of AYAs lives is critical in delivering quality care for this age group (Zebrack, Santacroce, Patterson, & Gubin, 2016).

The “Quality Cancer Care for Adolescents and Young Adults: A Position Statement,” outlines benchmarks for AYA models of care including early detection and diagnosis, timely referral to age-appropriate information and support services, initiation of treatment and promotion of adherence, healthcare providers knowledgeable of biomedical and psychosocial issues specific to AYAs, and AYA oncology-specific research (Zebrack, Mathews-Bradshaw & Siegel, 2010). The standard of AYA culture of care is patient-centered and utilizes a multidisciplinary team approach (e.g. social workers, fertility experts, nurse educators, sexual consultants, teachers, psychologists, cosmetic experts) to support patients in navigating young adulthood’s unique psychosocial issues (Bleyer, O’Leary, Barr, & Ries, 2006). Psychosocial service providers should practice with a developmental lens that balances acknowledgement of the barriers to development (e.g. premature confrontation with mortality, separation from peers and school during cancer treatment, increased dependence on parents, treatment intensity experienced as painful, traumatic, and extended, inability to participate in common teenage social activities, threats to reproductive capacity, and lack of social support and isolation after treatment) and areas of potential growth (e.g., meaning making in their diagnosis, enhanced resilience, and enhanced life perspective and awareness of their values) (Block, 2015; Zebrack & Isaacson, 2012). Social workers can act as brokers and advocates for AYAs and their families in attaining psychosocial treatment and resources specific to their needs throughout the care trajectory (Block, 2015).

**Unique Needs of AYAs.** AYAs face unique psychosocial challenges when battling cancer during their formative developmental years, such as identity and sexual development, struggles for autonomy, fertility preservation, neurocognitive effects, disruptions in schooling, and isolation from peer and family support networks (Shaw et al., 2015). Physiologically, AYAs are neurologically underdeveloped in the areas that control

impulses, foresee consequences, and mediate emotional responses to environmental stressors (Zebrack, Santacroce, Patterson, & Gubin, 2016). Psychologically, the prevalence of mental health disorders is the highest during young adulthood (Kessler & Wang, 2008). Psychological risk factors are exacerbated by the distress caused by a life-threatening illness that can manifest in anxiety and depression (Zebrack, Santacroce, Patterson, & Gubin, 2016). Anxiety and depression can impact quality of life and survival outcomes among AYAs with cancer, such as potential non-adherence with treatment, increase in physical pain, and higher disease morbidity (Lauer, 2015).

Individuals diagnosed with cancer during their AYA years, as compared with individuals diagnosed with cancer at an older age, may have had less opportunity to cope with stressful life events prior to diagnosis and less anticipation due to having been diagnosed with cancer at a less normative age in the lifespan (Merluzzi et al., 2001). AYAs tend to lack the range of coping skills and life experiences of older adult cancer patients (Lauer, 2015). Cancer treatment can create isolation from friends and family, especially for AYAs (Treadgold & Kuperberg, 2010). Connecting with a cancer peer support group may be helpful for some adolescents and young adults since it can afford opportunities to openly share their struggles, help others, and relate to peers who share similar circumstances (Treadgold & Kuperberg, 2010). Yet the diversity of ages and social needs across the AYA cancer population creates challenges with the design, recruitment, group composition, and sustainability of peer support services (Treadgold & Kuperberg, 2010; Carmack Taylor et al., 2007).

### **Problem Statement**

The unique challenges and concerns facing AYAs persist beyond cancer diagnosis and treatment (Quinn, Goncalves, Sehovic, Bowman, & Reed, 2015). AYAs tend to

experience an increase in distress at the time of transition to survivorship care (Kwak et al., 2013). Challenges with maintaining or developing new social relationships are commonly cited as one of the most important long-term issues for AYA cancer survivors (National Cancer Institute, 2006). Research is needed to help foster the maintenance and development of social relationships among AYAs and to identify the social support resources needed to improve their well-being (Warner et al., 2016).

### **Study Aims**

This study is designed to explore the social functioning of young adult cancer survivors during the transition from active treatment to survivorship care. The aims of this study are three-fold:

1. To explore *social isolation* among young adult cancer survivors (diagnosed between the ages of 18-25) during the transition process from active treatment to survivorship care and approximately 3 months later.
2. To explore *social support* among young adult cancer survivors (diagnosed between the ages of 18-25) during the transition process from active treatment to survivorship care and approximately 3 months later.
3. To explore the *self-efficacy for managing social interactions* of young adult cancer survivors (diagnosed between the ages 18-25) during the transition process from completion of active treatment to survivorship care and approximately 3 months later.

### **Research Questions**

1. What are the sociodemographic characteristics of study participants?
2. Are young adult cancer survivors experiencing impairment in social isolation, ability to participate in social roles and activities, self-efficacy for managing

social interactions, or satisfaction with social roles and activities during the transition from active treatment to survivorship care?

3. Are there significant changes in the social functioning of young adult cancer survivors on measures of social isolation, ability to participate in social roles and activities, self-efficacy for managing social interactions, or satisfaction with social roles and activities between the completion of active treatment and approximately 3 months later?

### **Study Significance**

This study contributes to the emerging literature examining the transition needs of AYA cancer survivors. This study will help to identify areas of social functioning that may be most challenging for AYAs during this transitional phase in the cancer care continuum. This study may also help to identify what to ask and how to screen AYAs about their social functioning prior to completion of cancer treatment. This study may help support oncology social workers in fostering opportunities for AYAs to stay involved socially throughout treatment. The findings from this study may be used to inform future psychosocial intervention development for AYAs in transition.

## **Chapter 2: Theories & Conceptual Models**

### **Introduction**

The theories and conceptual models used to inform this research have been selected for their utility in exploring the social functioning of AYA cancer survivors. The Theory of Emerging Adulthood (Arnett, 2000) provides the developmental context for this age group of 18-25 year olds. The Transactional Model (Lazarus & Folkman, 1984; Lazarus, 1999) and the Optimal Matching Model of Stress and Social Support (Cutrona & Russell, 1990) examine interactions between stress response, coping processes, and the social support system. The Social Ecological Framework (Bronfenbrenner, 1979; Bronfenbrenner, 1999) provides overarching context for the reciprocal relationship between an individual and his/her social environment. The applications of each theory/model in oncology research will be discussed. This chapter concludes with implications for future psychosocial oncology research applying these theories and conceptual models.

### **The Theory of Emerging Adulthood**

Understanding the psychosocial needs of AYAs involves appreciation of their unique developmental needs. The Theory of Emerging Adulthood (Arnett, 2000) proposes that emerging adulthood is a culturally constructed, distinct developmental phase of life for individuals aged 18-25 in industrialized societies characterized by relative independence from social roles and normative expectations. The three main areas of identity exploration in emerging adulthood are love, work, and worldviews (Arnett, 2000). Qualities of character, such as accepting responsibility for oneself, making independent decisions, and becoming financially independent, have been identified as criteria for the transition to adulthood, reflecting the emphasis on developing self-sufficiency during this



life period (Arnett, 1998). This theory has been debated in regards to its applicability across social classes (Hendry & Kloep, 2010). Arnett (2016) has used data from a national survey of 18 to 25 year olds to test this critique and found consistencies across social classes in the key features of the theory. He maintains that this theory can be a helpful developmental guide and that it should be grounded in a social, cultural, and historical context (Arnett, 2016).

The theory of emerging adulthood was applied as a conceptual framework in a research study that explored the ways that unmet psychosocial needs may change at various stages throughout the continuum of cancer care among 18-25 year olds (Millar, Patterson, & Desille, 2010). Participants were recruited from the membership database at CanTeen, the Australian organization for young people living with cancer (Millar, Patterson, & Desille, 2010). Study participants ages 18-24 were in various stages of treatment, recovery, and post-treatment for cancer, including one year or less since treatment, between one and five years since treatment, and five or more years since treatment (Millar, Patterson, & Desille, 2010). Participants completed the Depression, Anxiety, and Stress Scales (DASS-21; Lovibond & Lovibond, 1995), the Cancer Needs Questionnaire for Young People (CNQ-YP; Shakeshaft, Sanson-Fisher, & Girgis, 2006), and 24 supplemental questionnaire items identified in a review of previous qualitative research with emerging adults (Millar, Patterson, & Desille, 2010).

Results suggest that emerging adults' unmet psychosocial needs vary across the continuum of care and are related to the priorities identified in the theory of emerging adulthood (Millar, Patterson, & Desille, 2010; Arnett, 2000). Among individuals at or within one year since cancer treatment, the most prominent unmet needs identified were the need for age-appropriate hospital care, better food, and better leisure space and activities while in treatment (Millar, Patterson, & Desille, 2010). Among individuals

between one and five years since cancer treatment, the most prominent unmet needs identified were help with focusing on tasks and remembering things, help dealing with frustration, help with managing identity struggles, informational needs about what happens post-treatment, and parental over-protectiveness (Millar, Patterson, & Desille, 2010). Among individuals beyond five years since treatment, the most prominent unmet needs included help with focusing on tasks and remembering things, identity renegotiation and independence, and guidance about further educational or career paths (Millar, Patterson, & Desille, 2010). Taken together, these findings suggest that emerging adults need a time-sensitive and ongoing approach for monitoring their psychosocial needs and providing psychosocial services across the cancer care trajectory (Millar, Patterson, & Desille, 2010). The Theory of Emerging Adulthood (Arnett, 2000) provides context for identifying and addressing common psychosocial concerns experienced by young adult cancer survivors about identity development, loss of independence, and self-sufficiency.

### **The Transactional Model**

The Stress, Appraisal, and Coping Model, also referred to as the Transactional Model, developed by Lazarus & Folkman (1984) identifies cognitive appraisal and coping as mediators of stressful person-environment interactions and their immediate and long-term outcomes. Cognitive appraisal examines the process by which emotions are elicited as the result of an individual's subjective interpretation of important events and situations. There are two types of appraisal: (1) primary appraisal is the person's evaluation of an event or situation as a potential hazard to his or her well-being, and (2) secondary appraisal is the person's evaluation of his or her ability to handle the event or situation (Lazarus & Folkman, 1984).

Coping is an interaction between the person's internal resources and external environmental demands (Lazarus & Folkman, 1984). Coping involves a dynamic interplay of cognitive and behavioral efforts to manage specific external and/or internal demands that are initially appraised as exceeding the person's resources (Lazarus & Folkman, 1984). Coping is viewed as process oriented and contextual to the current stressor. There are no a priori assumptions about what may constitute good or bad coping. In problem-focused coping, efforts are made to change the *external* person-environment interaction causing the distress, such as problem solving, obtaining practical support, and time management strategies (Lazarus & Folkman, 1984). In emotion-focused coping, the *internal* meaning is altered to regulate stressful emotions, such as use of mindfulness strategies and obtaining counseling services (Lazarus & Folkman, 1984). Outcomes are informed by the person's judgment of the extent to which the encounter was resolved successfully, based upon the individual's goals and values and his or her expectations of the encounter (Lazarus & Folkman, 1984).

The basic tenets of the Stress, Appraisal, and Coping Model have been revisited over the years and are discussed in the sequel, "Stress and Emotion: A New Synthesis" (Lazarus, 1999). In the sequel, the concept of appraisal was expanded beyond perceptions of threat, harm, and challenge to include the individual's perceived coping potential, responsibility appraisals, goal relevance and congruence, and evaluation of the stressor's longevity (Lazarus, 1999). However, most evidence for the Transactional Model comes from laboratory-based experimental designs or cross-sectional survey research on the experience of heterogeneous, vicarious, and/or acute stressors only (Lazarus, 1993).

The updated Transactional Model (Lazarus, 1999) has been investigated for whether its hypothesized predictions about cognitive appraisals of stressors and the individual's emotional responses can be applied within the context of a cancer diagnosis

(Hulbert-Williams, Morrison, Wilkinson, & Neal, 2013). The study sample was composed of adult early stage cancer patients. Baseline, three-, and six-month self-report data were collected to examine appraisal components (e.g., problem focused coping potential, motivational relevance), core-relational themes (e.g., blame of self or other), and emotions (e.g. anger, guilt, hope/challenge, happiness). The study was designed to examine potential longitudinal variation of theoretically associated components of emotions and cognitions over time and cross-sectional exploration of specific cognitive predictors of emotions (Hulbert, Williams, Morrison, Wilkinson, & Neal, 2013).

Using a longitudinal research design, theoretically associated components of emotions and cognitions were examined over time. Few variables changed significantly over time and more significant correlations were found between theoretically unassociated components than for relationships hypothesized from theory (Hulbert, Williams, Morrison, Wilkinson, & Neal, 2013). There are many potential contributing factors in these differences, such as use of a different study population, use of a different statistical approach, the length of the study time period, or the inability to isolate cancer-related stress (Hulbert, Williams, Morrison, Wilkinson, & Neal, 2013).

The findings from the exploration of specific cognitive predictors of emotions with this study sample of cancer patients suggested partial support for the model at a general level in terms of cognitive appraisal influencing high proportions of emotional response to stress. However, Lazarus' (1999) hypothesis that each emotion is associated with specific cognitive appraisal components was not supported (Hulbert, Williams, Morrison, Wilkinson, & Neal, 2013). These findings suggest the model may have too much specificity related to individual emotions-cognitions associations, yet can still provide useful insights into general stress and coping processes (Hulbert, Williams, Morrison, Wilkinson, & Neal, 2013).

## **Optimal Matching Model of Stress & Social Support**

The Optimal Matching Model of Stress and Social Support (Cutrona, 1990) was developed to help identify and match the type of social support that is most beneficial to individuals following stressful events, both controllable and uncontrollable. The model involves exploration of the components of the social support system and the dimensions of stress (Cutrona, 1990). The basic components of the social support system are identified as emotional support, social integration/network support, esteem support, tangible aid, and informational support (Cutrona, 1990). Additionally, two dimensions of stressful life events are also included in the model: controllability and life domain affected by the event (Cutrona, 1990).

In uncontrollable stressful life events, emotional support is hypothesized to be optimally beneficial (Cutrona, 1990). Conversely, when a stressful event is controllable, problem-focused coping involving informational support and tangible aid are likely to be most beneficial (Cutrona, 1990). Additionally, esteem support is hypothesized to have better effects following controllable events (Cutrona, 1990). However, in the case of chronic illness, where many life domains (such as assets, social role, and achievement) are affected, multiple components of social support will be needed across multiple life domains (Cutrona, 1990).

While the Optimal Matching Model of Stress and Social Support (Cutrona, 1990) may seem simple in regards to the need to offer social support that matches the individual's level of need, this model continues to be tested empirically and complex methodological questions remain about how to best categorize social support components and stressful life events in the context of chronic illness. The model does not capture the dynamic process of meeting psychological needs throughout the course of stressful life events.

Optimal matching theory has been tested in a cross-sectional study of adult cancer patients and survivors (Merluzzi, Philip, Yang, & Heitzmann, 2015). Participants completed measures of received social support, physical debilitation, and psychological distress. Findings suggest that the relation between physical debilitation and distress is moderated by received social support. This moderating effect was much stronger at high levels of physical debilitation, suggesting increased sensitivity to the matching or mismatching of social support among individuals with high levels of physical debilitation. Results suggest that patients in treatment who needed received support, both instrumental (tangible assistance) and emotional, and who did not receive it fared worse than those who needed it and received it. Conversely, patients who did not need received support (low in disease impact) but received it fared more poorly than those who were low in disease impact but did not receive high levels of received support. In regards to differences in findings among survivors versus patients, results suggest that patients in treatment benefited from the matching of need and provision for both emotional and instrumental support, while survivors only benefited from the matching of emotional support (Merluzzi, Philip, Yang, & Heitzmann, 2015).

### **The Social Ecological Framework**

Consistent with social work values and practice, the social ecological framework posits that human development is a reciprocal relationship between an individual and his/her social environment (Bronfenbrenner, 1979). The environment is conceived as a nested structure, moving from the innermost circle (microsystem) to the mesosystem to the exosystem to the macrosystem to the outermost circle (chronosystem) (Bronfenbrenner, 1994). The microsystem involves direct interpersonal relationships, such as family, school, and peer group. The mesosystem involves the linkages and processes between two or more

settings involved in the individual's life (e.g. between home and school). The exosystem involves the linkages and processes between two or more settings, in which one does not contain the individual but in which events occur that indirectly influence processes within the immediate setting in which the person lives. The macrosystem involves the overarching pattern of micro, meso, and exosystems characteristic of a particular culture or subculture, with particular reference to the belief systems and culture embedded in each of the broader systems. Finally, the chronosystem encompasses change over time not only in the characteristics of the individual but also in the environment in which that person lives (e.g. changes in family structure, socioeconomic status).

The social ecological model has been adapted to inform the Social ecological Model of AYA Readiness for Transition (SMART) care model for AYAs with chronic health conditions transitioning from pediatric to adult health care (Schwartz, Tuchman, Hobbie, & Ginsberg, 2011). The social ecological framework enables exploration of interdependent relationships between families, medical providers, and outside individuals and institutions, such as neighborhoods, health care policies, religion, and culture, and how they affect the adjustment of youth with chronic illness (Schwartz, Tuchman, Hobbie, & Ginsberg, 2011).

### **Chapter Summary**

These theories and conceptual models help to provide context for the exploration of the developmental and psychosocial needs of young adult cancer survivors during the transition from active treatment to survivorship care. The Theory of Emerging Adulthood (Arnett, 2000) should be further explored for its application in psychosocial oncology research with AYAs, including studying potential shifts from common life stage priorities due to life threatening illness, potential differences in intimacy and relationships, and

varied social support network structures. Further longitudinal research can be conducted using the updated Transactional Model (Lazarus, 1999) to examine coping processes over time (Hulbert, Williams, Morrison, Wilkinson, & Neal, 2013). The Model of Optimal Matching of Stress and Social Support (Cutrona, 1990) provides inspiration for further examination of the various types of stressors encountered during cancer treatment, the range of social supports needed to successfully cope, and how to optimize and customize provision of the various types and modalities (e.g. face-to-face, online) of social support across the illness trajectory. This model invites open and ongoing communication between patients and their health care team about emotional stressors, relationship dynamics in their support system, and their social support needs and preferences throughout the continuum of care. The Social Ecological Framework (Bronfenbrenner, 1979) can be used in future clinical research to identify psychosocial intervention needs and to allocate psychosocial resources more efficiently and effectively among individuals and communities (Schwartz, Tuchman, Hobbie, & Ginsberg, 2011).

## **Chapter 3: Literature Review**

### **Introduction**

This chapter will discuss the literature review that was conducted to identify and explore the published literature about AYA cancer survivor transition from active treatment



to survivorship care. An overview of the search strategy and study selection criteria will be provided. The findings of the studies will be reviewed for their contributions to the field. The clinical and research implications will be discussed.

### **Overview of Search Strategy & Study Selection**

A literature search was conducted using PubMed, PsycINFO, and CINAHL to identify existing knowledge and resources about AYA cancer survivor transition from active treatment to survivorship care. All studies that defined the population of interest as “AYA” were included. There were no date or publication type restrictions. U.S. and international studies were included, but all studies had to be published in the English language. Each database was searched in its entirety, through December 2017. The search strategy involved the following terms related to specification of age range, cancer, and transition linked together via the AND operator: “AYA”, “transition”, “cancer”.

Database searches identified a total of 51 articles. After duplicates (19), studies focused on other aspects of care, e.g. end of life, disclosure, distress, substance use (7), studies focused on the transition from pediatric to adult healthcare (4), non-English (1), those focused on childhood cancer survivors (6), and pharmacological/medical (5) research were removed, 9 articles remained. Basic study characteristics, including full publication citation, study methods, and key findings, were recorded (see Table 1, p. 28).

### **Review of Findings**

The literature about AYA cancer survivor transition from active treatment to survivorship care published as of December 2017 includes position statements for AYA oncology care guidelines in the United States and Canada, discussion of survivorship and transition issues among AYA cancer survivors, discussion of cancer survivorship care models for AYAs and exploration of who treats AYA cancer patients, an integrative

literature review examining effective transition therapy for AYAs, and a qualitative evaluation of AYA cancer survivorship educational programming. First, the papers examining survivorship and transition issues among AYA cancer survivors will be discussed. Next, the cancer survivorship care models for AYAs will be discussed, including a paper exploring who treats AYAs and where they are being treated (e.g. community center, academic hospital). The position statements outlining oncology care guidelines for AYAs in the United States and Canada will be discussed. Finally, papers examining effective transition therapy for AYAs and AYA cancer survivorship educational programming will be reviewed.

AYA cancer survivors face unique medical, psychosocial, and behavioral late effects (Patterson, McDonald, Zebrack, & Medlow, 2015). Medical late effects such as an increased risk of developing second primary malignancies after treatment (Mulrooney et al., 2008; Soliman & Agresta, 2008), treatment-related cardiotoxicity (Mulrooney et al., 2008; Soliman & Agresta, 2008), increased risk of non-cancer mortality, especially from circulatory and respiratory diseases (Prasad, Signorello, Friedman, Boice, & Pukkala, 2012), and increased rates of diminished fertility (Knapp, Quinn, & Murphy, 2011) require ongoing monitoring and surveillance (Patterson, McDonald, Zebrack, & Medlow, 2015). AYA cancer survivors are managing the dual demands of transition to independent adulthood and transition from cancer patient to survivor, along with reduction in support from medical services (Patterson, McDonald, Zebrack, & Medlow, 2015). There are a number of barriers for AYA cancer survivors in receiving appropriate follow-up care including practical (e.g. financial, lack of or inadequate insurance coverage, and competing life demands/responsibilities), health care system related (e.g. lack of resources for survivorship focused care, need for provider survivorship education, lack of provider recommendation for long-term follow-up), and psychosocial/health related (e.g. PTSD

symptoms/anxiety, lack of perceived need for follow-up/lack of symptoms, and desire to put/keep cancer history in past) that must be addressed using tailored, risk-based care (Overholser, Kilbourn, & Liu, 2017).

In Victoria, Australia a focus group was conducted to explore the psychosocial needs of AYA survivors during transition from active treatment to survivorship care (Thompson, Palmer, & Dyson, 2009). Focus group participants identified concerns primarily related to 3 categories: finishing treatment, ongoing health concerns, and future directions (Thompson, Palmer, & Dyson, 2009). These findings are helpful indicators for clinical intervention development. Research findings were used to support the development of a practice framework by the onTrac@PeterMac Victorian Adolescent and Young Adult Cancer Service (Palmer & Thomas, 2008; Thompson, Palmer, & Dyson, 2009).

The National Comprehensive Care Network (NCCN) AYA Guidelines cite the larger NCCN Guidelines for Survivorship Care but also highlight three additional broad long-term follow-up care models informed by “risk-based” medical care (Kinahan et al., 2015). Risk-based care involves a systematic plan of cancer screening, surveillance, and prevention based on the survivor’s personal treatment history, comorbid health conditions, family history, and lifestyle behaviors (Kinahan et al., 2015). The three models for AYA survivorship care include cancer center care, primary care provider, or shared care (Kinahan et al., 2015). The choice of survivorship care model will depend on variables such as availability of resources and risk-stratification (Kinahan et al., 2015).

The role of the physician in transition planning is critical, yet provider characteristics and health care settings can vary greatly in AYA oncology care. Data from the AYA HOPE study was utilized to explore a sample of physicians treating AYAs in the United States (Parsons et al., 2015). Findings suggest that physician characteristics vary

significantly by cancer type and age at diagnosis, yet non-pediatric physicians in community settings treat the majority of AYAs with cancer (Parsons et al., 2015). Further research is needed to examine whether physician characteristics impact patient retention for follow-up care and cancer outcomes among AYAs (Parsons et al., 2015).

The Canadian Task Force on AYAs with cancer was established in 2008 to help address inequities in care among this population (Wilkins, D'Agostino, Penney, Barr, & Nathan, 2014). As emphasized in their position statement, transitions are ongoing and dynamic processes (Wilkins, D'Agostino, Penney, Barr, & Nathan, 2014). Specifically in regards to supporting AYAs in the transition from active treatment to ongoing surveillance/monitoring, there are unique challenges during this time period including redefining “normalcy”, reconnecting with family and peers, and managing fear and uncertainty associated with follow-up procedures and risk of cancer recurrence (Wilkins, D'Agostino, Penney, Barr, & Nathan, 2014). There should be multidisciplinary *and* multi-system support for AYAs with cancer and their families (Wilkins, D'Agostino, Penney, Barr, & Nathan, 2014). Additionally, parents/caregivers should be involved in transition planning to help foster the AYA's autonomy in the health care setting (Wilkins, D'Agostino, Penney, Barr, & Nathan, 2014). Further research is needed examining barriers and facilitators of successful transition, as well as interventions to empower AYAs to manage shifting demands and transitions across the care continuum (Wilkins, D'Agostino, Penney, Barr, & Nathan, 2014).

In 2009, an expert committee of 28 individuals representing cancer centers, academia, non-profit service agencies, and community-based care settings was convened by the LIVESTRONG Young Adult Alliance to develop a position statement to help enhance cancer care for AYAs (Zebrack, Mathews-Bradshaw, & Siegel, 2010). The position statement emphasizes that throughout the care trajectory quality care involves

timely detection, efficient processes for diagnosis, initiation of treatment, and promotion of adherence, access to health care professionals with specialized AYA knowledge and expertise, and specialized AYA research initiatives (Zebrack, Mathews-Bradshaw, & Siegel, 2010). In regards to facilitating the transition to survivorship care, sample strategies and potential outcome measures are outlined. The sample strategies highlighted include making survivorship care plans available to patients and other appropriate health providers, early education about the transition from pediatric to adult health care settings/providers, assistance in developing appropriate self-management behaviors, resources for managing co-morbidities and ongoing late effects, lifetime access to portable treatment records, and access to health insurance information (Zebrack, Mathews-Bradshaw, & Siegel, 2010). Some of the potential outcome measures include possession of a survivorship care plan, successful transition to adult health care settings, health services utilization, assessment of health literacy and health-related quality of life, and health insurance status (Zebrack, Mathews-Bradshaw, & Siegel, 2010).

However, it remains challenging to implement and test these strategies due to complex systems issues in the provision of health care services in the United States (Zebrack, Mathews-Bradshaw, & Siegel, 2010). There are multiple tiers of health care providers and varied cancer care delivery systems (e.g. community care, NCI-designated cancer centers). Additionally, there are challenges with recruitment of sufficient numbers of AYAs to research studies and clinical trials to power statistical analyses (Zebrack, Mathews-Bradshaw, & Siegel, 2010).

Educational programming for AYA cancer survivors is emerging in the field. The “After Cancer Care Ends, Survivorship Starts for Adolescents and Young Adults” (ACCESS AYA) program was developed to provide specialized education for community health care providers, AYA survivors, their families, and cancer patient advocates

(Vollmer Dahlke et al., 2017). In addition to educational sessions and medical briefs for providers, the ACCESS AYA program also developed 2 annual, half-day interactive educational sessions for survivors, friends and family, and community cancer advocates (Vollmer Dahlke et al., 2017). Findings from the evaluation of the ACCESS AYA program suggest that it appears to have succeeded in increasing awareness of AYA survivors as a unique population and building a sense of community among AYAs and their caregivers and advocates (Vollmer Dahlke et al., 2017). Interestingly, they also found an increased desire among AYAs to engage in self and community advocacy (Vollmer Dahlke et al., 2017).

Examination of effective transition therapy for AYAs remains limited in the field. An integrative literature review examining effective transition therapy for AYAs identified twenty-two studies that met inclusion criteria, but only four empirically examined interventions (Masterton & Tariman, 2016). The four empirically examined interventions were dynamic group therapy, an educational cancer retreat, an online cancer forum, and online cognitive-behavioral therapy. There were eighteen important components of potentially successful interventions that were identified in all twenty-two articles. The five components that were most commonly referred to included cancer education, coping, sexual identity, maintaining normalcy, and AYA support. These components should be considered in the development of specialized transition care for AYAs. It is important to note that AYAs treatment experiences seem to significantly affect their transition into survivorship care, and as such, transitional therapy should begin at diagnosis and should be individualized throughout the care trajectory (Masterton & Tariman, 2016).

## Implications

The unique psychosocial and medical needs of AYAs persist beyond cancer treatment. Building upon existing AYA oncology care guidelines and survivorship care models, there are many opportunities to help support AYA cancer survivors in managing the complex challenges of life post-treatment. Particularly, engaging AYAs themselves in the development and delivery of psychosocial services. As noted by Vollmer Dahlke and colleagues (2017), there is an increased desire among AYAs to engage in self and community advocacy. This collaborative engagement will help foster innovative ideas and solutions to ongoing areas of concern, such as adherence with follow-up, making healthy lifestyle choices, and social reintegration. This is an understudied and underutilized opportunity to involve patients themselves in collaborative research and psychosocial intervention development.

Additional research is also needed to study the feasibility and efficacy of various survivorship care models (Kinahan et al., 2015). Patients, families, health care providers, researchers, policy makers and advocacy groups should work together to ensure quality survivorship care (Kinahan et al., 2015). Patients and caregivers should be involved in the evaluation of existing programming and be encouraged to share their ideas and feedback throughout the care trajectory. Patient and caregiver feedback should be utilized in all aspects of care delivery, program development, and program evaluation.

Table 1

*Literature Review: AYA Transition from Active Treatment to Survivorship Care*

<b>Source</b>	<b>Methods</b>	<b>Key Findings</b>
Kinahan, K. E., Sanford, S., Sadak, K. T., Salsman, J. M., Danner-Koptik, K., & Didwania, A. (2015). <i>Models of Cancer Survivorship Care</i>	Data included peer-reviewed literature, workshop summaries, &	The three models for AYA survivorship care include cancer center care, primary care provider, or shared care.

for Adolescents and Young Adults. <i>Semin Oncol Nurs</i> , 31(3), 251-259. doi:10.1016/j.soncn.2015.05.005	clinical practice guidelines.	Additional research is needed to study the feasibility and efficacy of various survivorship care models.
Masterton, K. J., & Tariman, J. D. (2016). Effective Transitional Therapy for Adolescent and Young Adult Patients With Cancer: An Integrative Literature Review. <i>Clin J Oncol Nurs</i> , 20(4), 391-396. doi:10.1188/16.cjon.391-396	Integrative literature review of articles published between 2008-2015. Outcomes were evaluated using the Adaptation Model of Nursing.	Examination of effective transition therapy for AYAs remains limited in the field. The five intervention components that were most commonly referred to included cancer education, coping, sexual identity, maintaining normalcy, and AYA support.
Overholser, L., Kilbourn, K., & Liu, A. (2017). Survivorship Issues in Adolescent and Young Adult Oncology. <i>Med Clin North Am</i> , 101(6), 1075-1084. doi:10.1016/j.mcna.2017.06.002	Data included published articles, research studies, and care guidelines.	There are practical, healthcare system related, and psychosocial/health related barriers to follow-up care that must be addressed using tailored, risk-based care.
Parsons, H. M., Harlan, L. C., Schmidt, S., Keegan, T. H., Lynch, C. F., Kent, E. E., . . . Smith, A. W. (2015). Who Treats Adolescents and Young Adults with Cancer? A Report from the AYA HOPE Study. <i>J Adolesc Young Adult Oncol</i> , 4(3), 141-150. doi:10.1089/jayao.2014.0041	Review of data from the National Cancer Institute's population-based AYA HOPE study.	Physician characteristics vary significantly by cancer type and age at diagnosis, yet non-pediatric physicians in community settings treat the majority of AYAs with cancer.

Table 1 (cont.)

*Literature Review: AYA Transition from Active Treatment to Survivorship Care*

Source	Methods	Key Findings
Patterson, P., McDonald, F. E., Zebrack, B., & Medlow, S. (2015).	Data included published articles,	AYA cancer survivors face unique medical, psychosocial,



Emerging issues among adolescent and young adult cancer survivors. <i>Semin Oncol Nurs</i> , 31(1), 53-59. doi:10.1016/j.soncn.2014.11.006	research studies, and position statements.	and behavioral late effects. AYAs are managing the dual demands of transition to adulthood and to survivorship care.
Thompson, K., Palmer, S., & Dyson, G. (2009). Adolescents & young adults: Issues in transition from active therapy into follow-up care. <i>European Journal of Oncology Nursing</i> , 13(3), 207-212. doi:10.1016/j.ejon.2009.05.001	8 young people (5 females and 3 males), with an average age at diagnosis of 24 years and 8 months, participated in a 3 hour focus group.	Participants identified survivorship concerns related to 3 broad categories: finishing treatment, ongoing health concerns, and future directions.
Vollmer Dahlke, D., Fair, K., Hong, Y. A., Kellstedt, D., & Ory, M. G. (2017). Adolescent and Young Adult Cancer Survivorship Educational Programming: A Qualitative Evaluation. <i>JMIR Cancer</i> , 3(1), e3. doi:10.2196/cancer.5821	Qualitative evaluation of AYA educational programming.	Specialized education for community health care providers, AYA survivors, their families, and cancer patient advocates appears to have succeeded in increasing awareness of AYA survivors as a unique population and building a sense of community among AYAs and their caregivers and advocates.

Table 1 (cont.)

*Literature Review: AYA Transition from Active Treatment to Survivorship Care*

Source	Methods	Key Findings
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<p>Wilkins, K. L., D'Agostino, N., Penney, A. M., Barr, R. D., &amp; Nathan, P. C. (2014). Supporting adolescents and young adults with cancer through transitions: position statement from the Canadian Task Force on Adolescents and Young Adults with cancer. <i>J Pediatr Hematol Oncol</i>, 36(7), 545-551.</p>	<p>Reviewed heterogeneous sample of studies and recommendations, ranging from well-designed case-controlled investigations to opinions of respected authorities based on clinical experience, and reports of expert committees.</p>	<p>Transitions are ongoing and dynamic processes. A coordinated approach to support AYAs with cancer and their families must be multidisciplinary and multi-system – parents/caregivers must also be involved in the transition – facilitating the gradual evolution of the AYA's autonomy in the health care setting.</p>
<p>Zebrack, B., Mathews-Bradshaw, B., &amp; Siegel, S. (2010). Quality cancer care for adolescents and young adults: a position statement. <i>J Clin Oncol</i>, 28(32), 4862-4867. doi:10.1200/jco.2010.30.5417</p>	<p>The LIVESTRONG Young Adult Alliance convened a meeting of experts (clinicians, researchers, and advocates) in June 2009 to develop this position statement.</p>	<p>Quality care depends on 4 critical elements: timely detection, efficient processes for diagnosis, initiation of treatment, and promotion of adherence, access to specialized health care professionals, and specialized research.</p>

## **Chapter 4: Methodology**

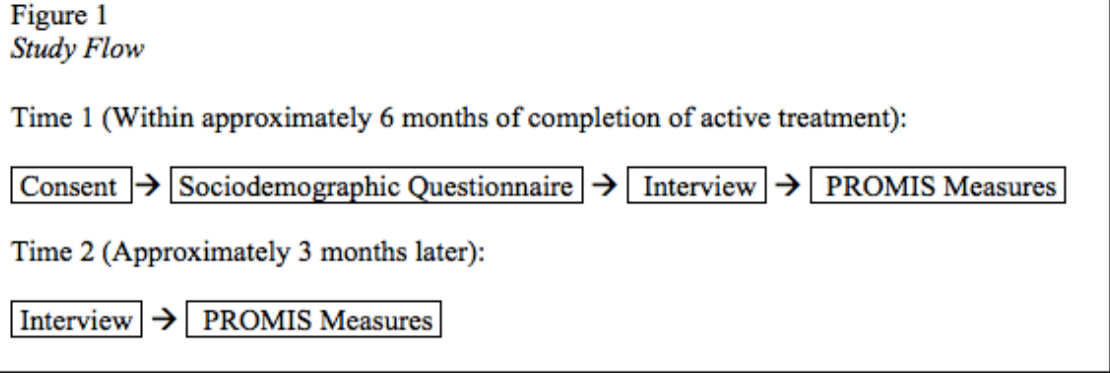
### **Introduction**

This chapter will discuss the key components of this research study, including the study design, study sample, study measures, and data management and analysis. The rationale for the study design and the choice of study measures will be provided. Procedures that were followed to enhance rigor will be discussed. The qualitative and quantitative data management and analysis software and the analytical approaches that have been used will be reviewed.

### **Study Design**

Using a concurrent embedded design (Creswell & Plano Clark, 2011), this study explored the social functioning of young adult cancer survivors (ages 17-25 at the time of cancer diagnosis; ages 19-27 at the time of study participation) during the transition from completion of active cancer treatment to survivorship care ( $N=13$ ). Qualitative interviews were the primary data source, with supplemental quantitative self-report measures used for descriptive purposes. Semi-structured qualitative interviews were conducted at two time points: within approximately 6 months of completion of active treatment and 3 months later to elicit young adult survivor perspectives about who has helped support them throughout treatment, perceptions about any psychosocial support resources that they may have accessed, experiences of social isolation, advice for other young adult cancer patients, and suggestions about how their healthcare team can continue to help support them. At the time of the first study interview, participants were at various points in the transition from active cancer treatment to survivorship care, such as at their last chemotherapy appointment, at a radiation appointment following completion of chemotherapy, in the hospital recovering post-bone marrow transplant, or at a 3 or 6 month follow-up visit.

During this transition process, questions often remain regarding post-treatment care and follow-up. The study flow will now be discussed (Figure 1, p. 33). First, consent for study participation was obtained. After consent was obtained, all participants received a listing of local cancer support community resources. Next, the sociodemographic questionnaire was completed and the qualitative interview was conducted. The qualitative interviews seemed to help in fostering participant retention and completion of self-report measures at both time points by engaging young adults. As has been examined by Rosenberg et al. (2016) using a comparison study of young adult cancer patients who participated in a qualitative interview and were also asked to complete a survey questionnaire versus patients who were only asked to complete a study questionnaire, patients who had also participated in qualitative interviews were more likely to complete survey questionnaires. At the end of the study visit, participants were asked if they would prefer to complete the four brief self-report measures of social functioning via paper and pen or via online survey. At the initial study visit, the majority of study participants ( $n=11$ ) completed the study measures with pen and paper. At the 3-month follow-up, the majority of participants ( $n=9$ ) completed the questionnaires electronically via Qualtrics survey. Institutional Review Board approval was obtained from the University of Texas at Austin. Approval to engage in recruitment efforts with patients from the pediatric and adult academic medical center where this study was conducted was obtained from the hospital research compliance office and the oncology division chief.



**Study Sample**

In collaboration with the Young Adult Oncology Program where this study was conducted, 13 young adult cancer patients were recruited over a period of approximately 5 months (from June 2017 – November 2017) from the pediatric and adult academic medical center. The eligibility criteria for study participation included being treated for cancer at either the pediatric or adult academic medical center in which this study was conducted, diagnosis with cancer between the ages of 18-25 years old, and being within approximately 6 months of the completion of active treatment at the time of study enrollment (as determined by referring healthcare provider). One study participant who was diagnosed with cancer 1 week prior to his 18<sup>th</sup> birthday has been included in the study sample. Exclusion criteria included diagnosis of brain tumor and transition to palliation. Informed consent was obtained from all study participants. Of the 13 patients who consented to participate in the study, one participant died prior to the follow-up interview. All other participants were reached for follow-up interviews and completion of study questionnaires. Participation retention was fostered by ongoing engagement with the adolescent and young adult cancer program.

Demographic information was collected via self-report from all study participants at the initial study visit (Table 2, p. 35). Participants reported their age (in years) at the

time of their cancer diagnosis, their age (in years) at time of study participation, cancer diagnosis, gender, race/ethnicity, educational attainment (at the time of study participation), health insurance status at the time of cancer diagnosis (insured/uninsured), and cancer treatment received (chemotherapy and/or surgery and/or radiation). At the time of cancer diagnosis, study participants were between the ages of 17-25 years old. At the initial study visit, study participants were between the ages of 19-27 years old. There was an almost equal representation of male ( $n=7$ ) and female ( $n=6$ ) study participants. There was racial/ethnic diversity among study participants: Hispanic/Latino ( $n=4$ ), non-Hispanic white/Caucasian ( $n=4$ ), Asian/Pacific Islander ( $n=3$ ), and mixed race ( $n=2$ ). Almost half of study participants had completed some college or attained an associate degree at the time of study participation ( $n=5$ ). The other participants had graduated high school or less ( $n=4$ ) or graduated college or higher ( $n=4$ ). Consistent with the most common cancer diagnoses among 15-24 year olds (National Cancer Institute, 2015), the most common diagnoses among study participants were acute lymphoblastic leukemia ( $n=4$ ), testicular cancer ( $n=2$ ), and Hodgkin's lymphoma ( $n=2$ ). The majority of patients received both chemotherapy and radiation ( $n=7$ ). Three participants were uninsured at the time of their cancer diagnosis.

Table 2  
*Participant Sociodemographics (N=13)*

	<i>n (%)</i>	Range
Age (in years) at the time of cancer diagnosis		17-25
Age (in years) at the time of study participation		19-27
Gender		
Male	7 (53.85)	
Female	6 (46.15)	
Race/Ethnicity		
Hispanic/Latino	4 (30.77)	
Caucasian/Non-Hispanic white	4 (30.77)	
Asian/Pacific Islander	3 (23.08)	
Non-Hispanic white & Asian/Pacific Islander	2 (15.38)	
Educational Attainment (at time of initial interview)		
Some College/Associate Degree	5 (38.46)	
College Graduate or Higher	4 (30.77)	
High School Graduate or Less	4 (30.77)	
Cancer Diagnosis		
Acute Lymphoblastic Leukemia	4 (30.77)	
Testicular Cancer	2 (15.38)	
Hodgkin Lymphoma	2 (15.38)	
Acute Myeloid Leukemia	1 (7.69)	
Non-Hodgkin Lymphoma	1 (7.69)	
Wilms Tumor	1 (7.69)	
Rhabdomyosarcoma	1 (7.69)	
Ewing Sarcoma	1 (7.69)	

Table 2 (cont.)  
*Participant Sociodemographics (N=13)*

	<i>n (%)</i>	Range
Treatment Received		
Chemotherapy & Radiation	7 (53.85)	
Chemotherapy, Surgery, & Radiation	2 (15.38)	
Chemotherapy	2 (15.38)	
Chemotherapy & Surgery	2 (15.38)	
Health Insurance Status at Time of Cancer Diagnosis		
Insured	10 (76.92)	
Uninsured	3 (23.08)	



## **Study Measures**

**Interview Guides.** Two semi-structured interview guides (see Appendix, p. 104) were developed specifically for this study. Study guides were developed based upon the AYA literature. All questions were then reviewed by and discussed with the Adolescent and Young Adult Oncology Program Manager and members of the dissertation committee prior to data collection. Each interview began by thanking participants for sharing their time. The first question asked participants about their talents and interests. This helped with rapport and often provided unique insights into their world. Participants were asked about who has helped support them during treatment and any support resources they may have accessed during treatment. Participant advice was solicited regarding what they would recommend as helpful to other young adult cancer patients, as well as their perceptions about what they may have found challenging and/or helpful if they accessed any psychosocial support resources during treatment. Participants were asked about experiences of social isolation during treatment and how they feel about navigating social situations as they transition into survivorship care. The interview concluded by asking how their healthcare team can continue to help support them, and if there is anything that they would like to share that they had not had the opportunity to discuss during the interview. This question enabled

participants to have the opportunity to discuss areas of concern and relevance that were not part of the interview guide, to elaborate on experiences discussed earlier in the interview, and/or to reflect upon the interview experience itself.

The follow-up interview guide begins by asking how they have been doing over approximately the past three months since the initial study interview. Participants were asked to describe who has helped support them in the transition to survivorship care, as well as any support resources that they may have accessed over the past three months. Their advice was solicited again about what they would recommend as helpful to other young adult cancer patients, as well as things that they may have found challenging and/or helpful in regards to accessing support resources. Participants were asked if they had experienced social isolation over the past 3 months, as well as if their feelings had changed at all about navigating social situations since finishing treatment. The interview concluded in the same way as the initial interview, by asking how their healthcare team can continue to help support them, and if there is anything that they would like to share that they had not had the opportunity to discuss during the interview.

**Self-Report Measures.** A sociodemographic questionnaire was developed specifically for this research study. At the initial study visit, participants were asked to provide their age (in years) at time of cancer diagnosis, age (in years) at time of study participation, cancer diagnosis, gender, race/ethnicity, educational attainment (at the time of study participation), health insurance status at the time of cancer diagnosis (insured/uninsured), and cancer treatment received (chemotherapy and/or surgery and/or radiation).

The Patient-Reported Outcomes Measurement Information System (PROMIS) is a set of person-centered measures that evaluates and monitors physical, mental, and social health in children and adults (HealthMeasures, 2017). The PROMIS measures are publicly

available for use. PROMIS uses Item Response Theory (IRT) to identify health domains and to calibrate PROMIS question responses in relationship to those domains (HealthMeasures, 2017). In item response theory, unique values are assigned to each item based on how likely people with different levels of the measured trait are to endorse an item. Each scale has a calibration sample and a centering sample. The short, fixed-forms that were used in this study are sets of questions that have been calibrated to the health domain and do not require computer software for administration (HealthMeasures, 2017).

In keeping with the study aims, the following four PROMIS measures were selected from the social health domain for adults and administered to all study participants at both study time points: Satisfaction with Social Roles and Activities - short form 8a (v2.0), Ability to Participate in Social Roles and Activities - short form 8a (v2.0), Social Isolation - short form 8a (v2.0), and Self-Efficacy for Managing Social Interactions - short form 8a (v1.0). Each of the questionnaires will be described in detail below.

The Satisfaction with Social Roles & Activities – short form 8a (v2.0) assesses satisfaction with performing one’s usual social roles and activities. There is no time frame provided to survey respondents. There are 8 questions, and each question has five response options ranging in value from one (not at all) to five (quite a bit). The general population was utilized for both the calibration sample and the centering sample of the survey. A higher T-score means more of the concept being measured. T-scores are categorized in ranges: within normal limits (45.0-80.0), mild impairment (40.0 – 44.9), moderate impairment (30.0 – 39.9), and severe impairment (20.0 – 29.9).

The Ability to Participate in Social Roles and Activities - short form 8a (v2.0) assesses the perceived ability to perform one’s usual social roles and activities. There is no time frame provided to survey respondents. Items are worded negatively in terms of perceived limitations (e.g. I have to limit the things I do for fun with others), but responses

are reverse-coded so that higher scores represent fewer limitations. There are 8 questions, and each question has five response options ranging in value from five (never) to one (always). A clinical sample of individuals with general chronic health conditions was used for both the calibration sample and the centering sample of the survey. A higher T-score means more of the concept being measured. T-scores are categorized in ranges: within normal limits (45.0-80.0), mild impairment (40.0 – 44.9), moderate impairment (30.0 – 39.9), and severe impairment (20.0 – 29.9).

The Social Isolation - short form 8a (v2.0) assesses perceptions of being avoided, excluded, detached, disconnected from, or unknown by others. There is no time frame provided to survey respondents. There are 8 questions, and each question has five response options ranging in value from one (never) to five (always). The general population was utilized for both the calibration sample and the centering sample of the survey. A higher T-score means greater symptom impairment (e.g. more social isolation). For the social isolation scale, T-scores are also categorized in ranges: within normal limits (20.0 – 54.9), mild impairment (55.0 – 59.9), moderate impairment (60.0 – 69.9), and severe impairment (70.0 – 80.0).

The Self-Efficacy for Managing Social Interactions - short form 8a (v1.0) assesses *current* level of confidence participating in social activities, getting help when necessary, and managing communication with others about their medical condition, including communication with healthcare providers. Respondents should be adults (ages 18+) with at least one chronic health condition. There are 8 questions, and each question has five response options ranging in value from one (I am not at all confident) to five (I am very confident). A higher T-score means more of the concept being measured. T-scores are categorized in ranges: within normal limits (45.0-80.0), mild impairment (40.0 – 44.9), moderate impairment (30.0 – 39.9), and severe impairment (20.0 – 29.9).

## **Data Management & Analysis**

**Qualitative Analysis.** The principal investigator transcribed all interview recordings within 24 hours of interview completion. The transcripts were stored and managed using Atlas.ti version 8.1.2 for Mac. Applied thematic analysis (Guest, MacQueen, & Namey, 2012) was used to identify and explore themes from participant interviews. First, the transcripts were reviewed to identify themes representing both implicit and explicit ideas within the data (Guest, MacQueen, & Namey, 2012). Next, codes and sub-codes were developed to represent identified themes (Guest, MacQueen, & Namey, 2012). There were 6 codes and 12 sub-codes that emerged from the interview data (Table 3, p. 45). These themes (codes) emerged when reviewing the interview transcripts by grouping together the ideas and experiences that participants discussed, such as interactions with members of their healthcare team or treatment effects experienced. The themes were further categorized into sub-themes to help elucidate the complexities of the key themes, such as “being there”, “staying strong”, and “treat me the same” helping to explain the broad theme of interactions with the support system. An iterative approach was used for codebook development. Three transcripts were randomly selected to develop the codebook draft. The principal investigator and a coding partner who is also an oncology social work PhD student coded the same three interview transcripts using the codebook draft. The codebook was revised and transcripts were re-coded until we reached 88% intercoder reliability. The salience of codes was determined using code frequencies (Appendix, p. 99). Code co-occurrences were computed to help explore the relationships between codes (Appendix, p. 99). When a text segment has two codes, such as a participant statement describing

advocacy efforts to learn more about treatment effects with a member of their healthcare team, this is classified in the Atlas.ti software as a “code co-occurrence” since both “advocating/staying informed” and “interactions with the healthcare team” were coded. By looking at the code co-occurrences, I was able to better understand how these concepts are related to each other, such as that advocacy is often occurring when participants are interacting with their healthcare team.

**Strategies to Enhance Rigor.** Multiple strategies were utilized throughout data collection and analysis to enhance rigor including the use of an audit trail, peer debriefing, reflexivity, and member checking. The COREQ: a 32-item checklist for interviews and focus groups (Tong, Sainsbury, & Craig, 2007) has been used to help foster rigor in all aspects of this study. An audit trail was kept throughout data collection including detailed notes after each study encounter. Peer debriefing occurred on a regular basis throughout data collection with a fellow oncology social work doctoral candidate. Additionally, my dissertation chair provided emotional support and resources about trauma stewardship to help cope with secondary trauma experienced during data collection. My clinical experience as pediatric medical social worker and the potential impact of my clinical training on interview administration was considered.

Member checking was conducted following completion of data analysis. A one-page sheet was developed summarizing the key themes and sub-themes that were found in this study (Appendix, p. 105). The summary of findings was emailed to six participants who had expressed their interest at the time of study participation in learning about the study findings. Participants were asked if the findings make sense with their experiences, if there

was anything that didn't make sense or that they would change, if there was anything that they thought was missing, and what were some ways that we could use these findings to help other young adults with cancer. Three participants responded with their feedback affirming the study findings with their experiences (Appendix, p. 100).

**Quantitative Analysis.** All questionnaire data was labeled using unique participant ID numbers, managed using SPSS Version 24 and Excel, and saved in a password protected folder on UT Box. Descriptive statistics were computed for participant sociodemographic characteristics. The internal consistency of the PROMIS measures was checked at both time points using Chronbach's alpha. A missing data value analysis was conducted at both time points. Raw scores were saved in Excel files and submitted to the HealthMeasures Scoring Service. The HealthMeasures Scoring Service returned calculated T-scores for all participants via email. Descriptive statistics for the survey measures were calculated using the participant T-scores at both time points. To examine if participants were experiencing impairment on any of the four measures of social functioning, categorical variables were created to compute the percentage of participant T-scores within each range (e.g. within normal limits, mild impairment, moderate impairment, or severe impairment) on each measure. To examine if there were any significant differences between groups in participant T-scores at Time 1 and Time 2 on any the four measures, paired samples t-tests were computed.

## Chapter 5: Qualitative Findings

### Introduction

This chapter will discuss key themes from the semi-structured qualitative interviews conducted with study participants ( $N=13$ ; ages 17-25 at the time of cancer diagnosis; ages 19-27 at the time of study participation) within approximately six months of the completion of active treatment and again three months later. Of the 13 initial interviews, 10 were conducted in-person at the hospital, two started in-person at the hospital and were completed via phone, and one was conducted off-site at a private space in a coffee shop chosen by the participant for geographic convenience. At the time of the first study interview, participants were at various points in the transition from active cancer treatment to survivorship care, such as at their last chemotherapy appointment, at a radiation appointment following completion of chemotherapy, in the hospital recovering post-bone marrow transplant, or at a 3 or 6 month follow-up visit. During this transitional phase in the care trajectory, questions often remain regarding post-treatment care and follow-up. As described by one of the study participants during her 3 month follow-up interview, "... *I mean I'm gonna go back to it pretty soon, like I have more scans and stuff in March and whatnot so it's not like I'm completely out of the woodwork...*" (P13, age 22, F, Non-Hodgkin's lymphoma).

Of the 13 participants who consented to participate in the study, one participant died prior to the follow-up interview. All 12 follow-up interviews were conducted via phone. Flexibility in regards to participant choice of interview modality (e.g. phone, in-person



during follow-up medical visit, off-site at a private location of the participant's choosing) helped to minimize participant burden and to foster participant retention. The principal investigator, a licensed clinical social worker, conducted all study interviews. All interviews were audio recorded and transcribed by the principal investigator.

### **Key Themes**

Study participants expressed their willingness to share their experiences for this research study to help ease the care journey for other young adult cancer patients. The 6 key themes and the 12 sub-themes will be presented (Table 3, p. 45). Key themes from participant interviews will be discussed in the context of the ongoing developmental, psychosocial, and medical needs of young adult cancer survivors. Participant quotes will be incorporated throughout, with notation of their current age (in years) at the time of study participation, their gender (M / F), and their cancer diagnosis.

Table 3  
Key Themes & Sub-Themes

<b>Themes</b>	<b>Sub-Themes</b>
Interactions with Support System	Being there
	Staying strong
	Treat me the same
Interactions with the Healthcare Team	Connection & Relationship building
	Seeking knowledge & Engaging in advocacy
Treatment Effects	Uncertainty, Loss, & Changes in Identity
	Ups & Downs of Physical Symptoms
Coping Strategies	Keep busy
	Keep a positive vibe
Support Resources	Support needs change over time
Post-Treatment Experiences	Trying new things to cope with losses

### **Interactions with Support System**

The first theme that emerged was Interactions with Support System. The key sub-themes that emerged about participant interactions with their support system include “Being there”, “Staying strong”, and “Treat me the same”. Participants openly discussed their interactions with their friends and family throughout cancer treatment. These social interactions have been explored using a developmental lens that acknowledges the tensions of seeking independence and autonomy during young adulthood (Arnett, 2000) while simultaneously needing to rely on family and friends for support and assistance during and after cancer treatment. The most frequently referenced members of their support system were friends, parents, and siblings. Each of the sub-themes of “being there”, “staying strong”, and “treat me the same” will be discussed.

**Being there.** Participants usually identified one primary support person who was consistently there with them throughout treatment. This person was identified as their mother, sibling, or partner. This person filled many functions and responsibilities, often described as going through treatment with them as if they themselves had cancer. One participant describes how much her mother has supported her, saying “*She has equally fought this, as if she had it herself....all of the inpatient stays, all the times that I’ve gone to the ER...*” (P01, age 19, F, Hodgkin’s lymphoma). Another participant describes the unwavering support he received from his sister, “*mostly my sister, my sister was 100%, she was there when I would be admitted, she would be there when I was in treatment or*

*procedures...it was basically like she was going through cancer as well” (P04, age 24, M, Acute lymphoblastic leukemia).*

Participants often described the reactions of their loved ones at the time of their cancer diagnosis. One participant describes the uncertainty of how his cancer diagnosis would impact his relationship, “...*it was kind of like right at about our year mark of being together, you know the cancer hit and...it could’ve gone one of two ways with our relationship, I’m glad it got us stronger and closer together...*” (P09, age 25, M, Testicular cancer). Another person describes her boyfriend who lives out-of-state coming to be with her in the wake of her cancer diagnosis, saying “...*as soon as we found out I was actually supposed to meet his family for Thanksgiving...so he actually changed his tickets, cancelled mine, and he flew here and met my whole family...*” (P02, age 22, F, Wilms Tumor). Sometimes relationships were even mended in the wake of the cancer diagnosis, as one participant discusses, “*my Mom really stepped up considering that up until the day of my diagnosis we’d been estranged for almost 10 years*” (P12, age 23, M, Acute myeloid leukemia).

Participants shared how much their primary support person helped them navigate the medical system. One participant described the tireless help his mother has provided in managing his care, saying “*My mom was meticulous at writing down every single note about any kind of doctor visit, treatment, everything, blood test. I’m pretty sure she has my blood pressure from every single visit...*” (P09, age 25, M, Testicular Cancer). Another patient describes the advocacy and care coordination assistance his Mother provides, saying “*you know Mom has really become like a, basically, like a case manager for me...her whole life has been turned over to umm you know helping me with my cancer and my recovery*” (P03, age 21, M, Acute lymphoblastic leukemia).

There were challenges discussed with loss of friendships and social stigma. Participants describe the loss of some friendships in the wake of their cancer diagnosis due to their friends not being emotionally equipped to handle their diagnosis. One participant describes, *“I’m not gonna sugarcoat it, I have friends who umm I’m not friends with anymore because of this situation”* (P05, age 25, M, Testicular cancer). Participants share how devastating it can be during treatment to see their friends continuing to live their lives. One participant (P03, age 21, M, Acute lymphoblastic leukemia) shares that:

*The thing that sucked the most was when I had my stroke and everyone else was going off to school and I was not, that was the hardest time I think. And you know when they came back they had these great stories and you know, my story was that for 2 and half months I was on my death bed practically and just scraped by and I’m still you know basically handicapped, but that was the hardest time when people were doing all of these great things, and you know everyone else gets to do very cool things, you know I was jealous, I was bitter, I was upset...it’s a bummer you know cause you’ve been working so hard going to launch off like that like everybody else and then it gets halted immediately just like that...*

He describes profound loss physically and socially. He was in his senior year of high school at the time of his cancer diagnosis and he was getting ready to head off to college. There are also strong perceptions of social stigma, such as *“I was sick, no one wants to be around a sick person...and being so young, it’s really hard, and not a lot of people get it. Umm and it’s weird because everyone else is like living their life...”* (P02, age 22, F, Wilms Tumor). Social isolation seems to be exacerbated by seeing friends’ activities posted on social media. One participant describes how much she misses being involved in theatre production activities that she used to participate in at college and seeing her friends activities shared on Instagram, *“...it’s been kind of difficult being chained to an IV pole, not really 100% of the*

*time but kind of, cause like on Instagram I would see all of this like, the people that I went to school with doing all these really cool productions”* (P01, age 19, F, Hodgkin’s lymphoma). Another participant describes his friends being too busy managing their social and professional commitments and responsibilities, such as parenting and working, to come to the hospital to visit with him.

The physical effects of treatment, such as fatigue and nausea, seem to compound communication difficulties with friends and family. One participant describes, “...*I was feeling sick all of the time and I was the only one that really knew exactly what I needed and it’s hard to communicate that to other people...*” (P02, age 22, F, Wilms Tumor). Another participant describes how when he wasn’t feeling well it was really hard feeling like he always had to fake a smile and talk with people who came to visit him, “...*you’re not being rude it’s just the fact that you’re not feeling so well...you just wanna be left alone you know, you just wanna be in your own like, bubble*” (P04, age 24, M, Acute lymphoblastic leukemia). Participants also describe frustration when people say that everything is going to be alright, such as “...*when someone just tells you like, you know, everything’s going to be fine...they kinda just need to listen to you...*” (P05, age 25, M, Testicular cancer). Another participant shares her frustration with hearing that it’s going to be alright from her parents, saying “...*and it’s kind of annoying cause when your parents are like oh, it’s gonna be ok, and sometimes that’s not really what you want to hear, and you get really tired of it...*” (P10, age 22, F, Acute lymphoblastic leukemia). Despite natural tendencies to provide reassurance, study participants are emphasizing that they just want to be heard and validated. Study participants recount meaningfully the friends and family who were physically there with them throughout treatment and the practical support from loved ones who help them manage their illness, such as taking notes during medical visits and arranging follow-up care.

**Staying Strong.** Participants consistently emphasized needing their support system and needing to be surrounded by loved ones but at the same time not wanting to burden and/or upset their family and friends. This dynamic seems to have adaptive functionality in terms of maintaining stability between patients and their loved ones throughout the ups and downs of treatment, yet may inhibit help seeking and exacerbate social isolation during times of distress. As one participant describes, “*I think a big part of it is my family, I stay strong for them because it’s kinda like if I break down they’re trying to stay strong for me as well, so I can’t, I don’t allow myself, or if I do I have to do it on my own, I cry by myself in private*” (P05, age 25, M, Testicular cancer). Another participant describes not wanting to burden her Mother saying, “*...they’re already emotionally distraught and it’s hard to ask someone that’s already freaking out to help you*” (P02, age 22, F, Wilms Tumor).

It also seems that there is an inverse relationship between perceived worry and disclosure about distress, such that the more participants perceive their loved ones are worried about them the less likely they become to share their distress with them. One participant discusses the effects of hiding her emotions to protect her parents, “*...so I kind of just tried to like, just push through everything, just be like I’m fine, I’m fine, I’m fine, cause like they were happier in that way so that kind of makes you feel more like alone...*” (P13, age 22, F, Non-Hodgkin’s lymphoma). It seems that throughout treatment as levels of uncertainty change and the intensity and duration of physical treatment effects varies, so do experiences of social engagement and social isolation. Some participants describe accessing counseling resources and feeling more comfortable to ask questions to the counselor that their friends and family didn’t ask because they were too afraid to know the real answer. Another participant emphasizes staying strong for himself because “*...all you really have at the end is yourself*” (P07, age 24, M, Acute lymphoblastic leukemia). One participant shares critical insights about communication strategies for healthcare providers to use when

assessing motivation, describing how *“Everybody asks, what is your reason for being alive? You don't have one, because you have a hundred. What you should be asking is, what is your reason for getting up this morning? You know, what is your goal, TODAY?”* (P12, age 23, M, Acute myeloid leukemia).

**Treat me the same.** Participants emphasized having control over if, when, and with whom they discussed their cancer diagnosis and treatment. With friends whom they had known prior to their cancer diagnosis, they wanted to be treated in the same way as prior to their cancer diagnosis and to talk about the same age appropriate social things when they are together. They share feeling caught off guard if someone asks them to talk about their cancer diagnosis and/or treatment and in some instances they withdraw from the interaction. One participant describes his feelings about talking about his cancer diagnosis and treatment, saying, *“...Every time I bring it up, it's fine, but when somebody asks me, like oh you know, remember when you went through this, and that's, that's the part that I don't really like, that's the part when I ignore you and walk away”* (P04, age 24, M, Acute lymphoblastic leukemia). Some participants also describe feeling frustrated with being called “strong” and “inspirational”. Such comments may be perceived as threats to their individuality, and young adults may be more sensitive to such threats during such a critical developmental period of identity formation.

Participants describe enjoying opportunities to talk with their friends during their hospital visits about anything non-cancer related, such as sports. This seems to enable feelings of normalcy and also provides distraction from the physical and mental anguish of treatment. When participants experience changes to their physical appearance due to treatment effects they face ongoing challenges with being perceived differently by their peers. One participant describes this struggle, saying *“I wanted to be seen as (pt name) beforehand...I was you know, (pt name), (pt name) has cancer, couldn't separate those*

*two... it took a toll on me especially during treatment and shortly after treatment” (P09, age 25, M, Testicular cancer). Another participant describes how she perceives that her friends now treat her like she is “fragile” and always ask her how she is doing, saying “...I mean part of it is just like genuine like how are you, but then part of it is also like a stigma that kind of is like associated with you...oh like that's the girl who was sick” (P08, age 19, F, Hodgkin’s lymphoma).*

### **Interactions with the Healthcare Team**

The next theme that emerged was Interactions with the Healthcare Team. The two sub-themes that emerged about interactions were the healthcare team were “Connection & Relationship Building” and “Seeking Knowledge & Engaging in Advocacy”. There was only one question towards the end of the interview guide specifically prompting discussion about how the healthcare team can help provide support, but participants consistently shared their perceptions of their healthcare team and their treatment experience throughout the study interviews. AYA cancer care in the United States is still delivered in both pediatric and adult oncology settings. In the pediatric setting AYAs often describe feeling isolated due to being the oldest while in the adult setting AYAs often describe feeling isolated due to being the youngest. Participants in this study were treated in an academic medical center across both the children’s hospital ( $n=9$ ) and the adult hospital ( $n=4$ ). Participants commented on their experiences as a young adult being caught between pediatric and adult care settings. Participants treated in the pediatric setting discussed being the oldest on the unit while participants treated in the adult setting discussed being the youngest. A couple of participants would alternate their chemotherapy treatments between the academic medical center and their local community cancer center. One participant describes how “*I would walk in, especially at [local community cancer center name], like I was just the **youngest** person by far...like you see all these like 40, 50, 60 year olds” (P08, age 19, F,*



Hodgkin's lymphoma). Some participants were transferred from their local community hospitals and cancer centers to the academic medical center for specialized treatment and clinical trials enrollment. Participants who relocated to receive treatment at the academic medical center often discussed increased burden being separated from their family and friends. The key sub-themes of "Connection & Relationship Building" and "Seeking Knowledge & Engaging in Advocacy" will be discussed.

**Connection & Relationship Building.** As young adults, and especially with the intensity and duration of cancer treatment, participants are seeking to connect with their healthcare team on a deeper level. This goes beyond communication about their cancer diagnosis and treatment, such that they also share conversation about social interests and activities. One participant describes the support she received from her nurses reflecting that they are always willing to go above and beyond. Another participant describes her interactions with the AYA program manager saying "*in the beginning when I got the g-tube I was like sending her pictures and pictures... and we talk about things now like not even g-tube related, but just like hey, did you see the beauty and the beast movie?*" (P01, age 19, F, Hodgkin's lymphoma). One participant recounts meaningfully her relationship with her social worker throughout treatment and the specialized resource assistance that she was able to provide for her.

Participants who have had lengthy hospitalizations post-bone marrow transplant describe an even deeper level of connection with their care team. One participant with leukemia discusses how during his 6 week hospitalization post-bone marrow transplant most of his nurses would work 3 days straight and he would have them multiple times and become comfortable with them, even joking them "*they're like is there anything you need, I'm like if you could bring me a bucket of beer*" (P07, age 24, M, Acute lymphoblastic leukemia). Participants shared thoughtful ways in which their care team members helped

ease their burden, such as *“The nurses made a dartboard for me when they thought I was going to relapse again”* (P10, age 22, F, Acute lymphoblastic leukemia). Even post-treatment, another patient with leukemia describes the special meaning that his relationships with his care team still hold, describing how *“...if not for cancer I wouldn’t know these people, but they are, you know, people that love me, and they’re people that I love”* (P03, age 21, M, Acute lymphoblastic leukemia). During another post-treatment interview, one participant describes hearing about her nurses getting married and having children and seeing them being content with their lives moving forward also makes her feel more comfortable with her own life moving forward.

Throughout study interviews, participants laughed frequently and used humor to build rapport with healthcare team members and to cope with the treatment process. One participant describes how her healthcare team uniquely appreciates her morbid sense of humor saying, *“...if I walk outside probably, I’d be hard pressed to find someone who thinks like my comment about my nice coffin that I got at Costco is very funny”* (P01, age 19, F, Hodgkin’s lymphoma). Another participant jokes about the awkwardness of trying to flirt with someone in the pediatric hospital, saying *“I may’ve tried to hit on someone once who was in the waiting room...but then I realized they were too young (laughter) and I was like forget it, I’m in a children’s hospital so...”* (P06, age 27, F, Ewing sarcoma). One participant describes using humor in the wake of his cancer diagnosis, *“...people were crying and I’m like why are you crying cause I ain’t dying (laughter)...and I’m like relax, I’m still here (laughter). So I tend to like joke around with my situation, but I try to make, you know, positive things about it”* (P07, age 24, M, Acute lymphoblastic leukemia). When providing cancer care for young adults, humor should be appreciated and fostered as a healthy coping mechanism.

However, some participants experienced challenges with their care team and expressed concerns regarding communication difficulties and unaddressed mental health needs. Challenges with communication are a source of frustration. Sometimes there appears to be a mismatch between anticipatory guidance provided and symptoms experienced, “...just kind of all along I kind of felt like they've given me instances of false hope, like oh this will be easy, or you're not supposed to feel this or whatever, and like you end up feeling it” (P08, age 19, F, Hodgkin’s lymphoma). One participant describes struggles with how his physician communicated with him, noting “I just wish sometimes they would put themselves a little bit in someone's shoes, and not say things so bluntly and be more optimistic to bring optimism for the patient” (P05, age 25, M, Testicular cancer). Another participant emphasizes “You really do need to create a dialogue with your doctors, not just a, umm, patient/doctor relationship, it needs to be more than that for cancer, specifically because your symptoms are gonna change...” (P12, age 23, M, Acute myeloid leukemia). In a post-treatment interview, one participant emphasizes that she wishes her mental health needs had been addressed during treatment. She emphasizes how physicians should be assessing mental health needs throughout treatment, “...and then if you just say like I'm struggling a lot with like panic attacks or with depression...they can be like ok, well here are some resources that can help you...there's just no check-in about like mental health like whatsoever” (P08, age 19, F, Hodgkin’s lymphoma).

**Seeking Knowledge and Engaging in Advocacy.** AYA patients in the 20- to 29-year old age group are significantly more likely to report an unmet need with regard to receiving age-appropriate information about their cancer (Coccia, 2018). Participants consistently emphasized seeking knowledge about their cancer diagnosis and treatment and making their voice heard in treatment decision-making processes. This was most commonly discussed in response to the interview guide prompt about what participants would

recommend as helpful to other young adult cancer patients. Especially as young adults, being able to openly express themselves and feeling heard and valued by their care team is critically important. One participant contrasted her first experience with cancer treatment when she was diagnosed and treated as an adolescent and her parents were more actively involved in decision-making, versus her most recent treatment for her cancer recurrence as a young adult where she has taken leadership in the treatment process. She describes how *“I would always ask for my roadmap to know what’s coming up, even when they would tell me there’s a lot of what if’s, I would be like well, explain every single what if to me”* (P10, age 22, F, Acute lymphoblastic leukemia). Especially in the context of so much uncertainty during cancer treatment, being fully informed can help enhance feelings of control, foster self-efficacy for managing treatment effects, and promote involvement in healthcare decision-making. Being fully informed also enables patients to be able to weigh the risks and benefits of treatment approaches and to advocate effectively for their needs and preferences.

Participants emphasize asking questions to their healthcare team because it’s much worse to have the questions floating around in their own head. One participant recommends for other young adult cancer patients to *“...educate yourself about what's going on you know, what you're being treated with, how you're being treated, what's going into your body, as well as research the different resources that you can take advantage of”* (P09, age 25, M, Testicular cancer). Participants recount meaningfully receiving direct information from their care team about potential treatment risks and treatment effects. One participant shares his experiences when he was first transferred to the academic medical center and was meeting with his new nurse practitioner, describing how *“... she explained to me about graft versus host and all of those types of things and after I learned that I felt a lot better about it because um, I'm able to identify those types of issues and I'm able to take time to comprehend*

*what I may have to go through*” (P12, age 23, M, Acute myeloid leukemia). Conversely, when participants receive unclear information from their treatment team this can exacerbate feelings of stress and uncertainty. During a post-treatment interview, one participant shares how her doctors were vague about what causes lymphoma and she continues to worry about her lifestyle and nutrition choices since she has returned to college. She describes how “*I don't know if what I'm doing is right or wrong or if it's a big deal or not a big deal, you know balancing like I just wanna hang out like and like drink or whatever with my friends versus like this is really not good for me.*” (P13, age 22, F, Non-Hodgkin’s lymphoma). She is experiencing tension with wanting to engage in age-appropriate social activities with her friends but also feeling cautious of her lifestyle choices and potential health risks. Participants consistently emphasize seeking information and guidance from their healthcare team to help them anticipate health concerns that may arise post-treatment.

### **Treatment Effects**

The next theme that emerged was Treatment Effects. The key sub-theme that emerged in regards to psychological treatment effects was “Uncertainty, Loss, & Changes in Identity”. The key sub-theme that emerged in regards to physical treatment effects was “Ups & Downs of Physical Symptoms”. Even though the interview guide did not provide any prompts to discuss treatment effects, study participants frequently discussed both the physical and psychological effects of cancer treatment. At the 3-month follow-up, the physical and psychological effects of treatment persisted, to varying extents depending upon diagnosis and type(s) of treatment received. Participants often discussed not being able to begin to process what actually happened until after the completion of treatment. This appears to be adaptive in terms of conserving energy in the mind and body to be able to manage physical symptoms during treatment. Each of the sub-themes regarding

“Uncertainty, Loss, & Changes in Identity” and “Ups & Downs of Physical Symptoms” will be discussed.

**Uncertainty, Loss, & Changes in Identity.** At the completion of active treatment, young adult cancer patients are managing the dual demands of the fear of cancer recurrence and the uncertainty of social reintegration with their peers and with their school/career. Participants often describe conflicting emotions, such as “...*sometimes I'm angry, sometimes I'm just sad, and sometimes I'm just like you know, who cares it's over - even though I don't feel that way*” (P02, age 22, F, Wilms tumor). Participants describe ongoing uncertainty with their prognosis and often struggle with whether or not they will be able to maintain employment or return to college after completing treatment. Participants describe the ongoing anticipation of being in remission, saying “*there's always this sense of you know hoping that you can get, or you get told that you know you're in remission, I think that's still something I'm waiting on, I think for a while I was gonna get my period back, but I got that back so I think that was a little exciting...*” (P06, (P06, age 27, F, Ewing sarcoma). Some participants share how it can feel more stressful being discharged from the hospital since their health is not monitored as frequently on an outpatient basis. Participants describe the anticipation of “normalcy”, such as returning to college post-treatment, but then being taken off-guard when it doesn't feel the same. One participant describes how much differently it felt when she returned to college than she had anticipated it would, saying “...*it was kind of like once I'm back at school like...that's when everything will be normal again and I'll be happy and then it was like, like why am I feeling like so overwhelmed and anxious...*” (P08, age 19, F, Hodgkin's lymphoma). Another participant shares how “...*it's weird, it's like kind of wishing things just like get back to normal but like not actually knowing what's going to happen so*” (P10, age 22, F, Acute lymphoblastic leukemia).

There should be acknowledgment of the loss experienced by young adults diagnosed with cancer during their formative years of identity development and exploration. Participants describe changes in their identity pre- and post-cancer diagnosis. Participants describe questioning their sense of self, noting that during treatment “...*you’re gonna get to that point where you’re just gonna really doubt yourself, not only if you’re gonna live but if you’re gonna be able to be the same person afterwards*” (P09, age 25, M, Testicular cancer). One participant strongly asserts that you are no longer the same person, describing how “...*you’re not getting back to where you were, that’s done, you’re not that person anymore... your whole mindset, your whole understanding of yourself and your body is going to be completely different*” (P12, age 23, M, Acute myeloid leukemia). Age at the time of cancer diagnosis and the severity of physical treatment effects appear to moderate the impacts of cancer on identity development. Patients who are younger at the time of cancer diagnosis and who experience more severe physical treatment effects seem to struggle more with changes in their identity in the wake of their cancer treatment.

Physical treatment effects, particularly changes in body image and feelings of body betrayal, seem to exacerbate feelings of uncertainty about social reintegration post-treatment. Female participants discuss concerns about wearing wigs and the social stigma of being bald. One female participant notes how “*it’s just not comfortable to wear a wig all the time... you don’t see very many like bald women in our society...it’s like a very visual thing of like what happened to you, you know?*” (P08, age 19, F, Hodgkin’s lymphoma). A couple of female participants mentioned utilizing the wig bank and participating in the Brave Beauty in the Face of Cancer Class at Sephora. One participant shared how nice it felt meeting other young adult cancer survivors and Sephora staff who were also cancer survivors. Male participants also noted changes in their physical appearance during treatment, particularly loss of facial hair and muscle mass. Some participants describe

feelings of betrayal by their bodies. Participants frequently note associations between achieving post-treatment medical milestones, such as port removal, and achieving steps towards “normalcy”. One participant describes feelings of relief after getting his port removed, comparing it to how it felt after getting his braces off and running his tongue over his teeth, but also the psychological aspect of it, noting *“the first day or two I was kinda just like prodding my chest, like wow, you know it's just my skin, there's nothing else there, that's awesome...and psychologically it's I want to have all of the foreign stuff out of me so that's like a nice step to normalness”* (P03, age 21, M, Acute lymphoblastic leukemia).

**Ups & Downs of Physical Symptoms.** Participants consistently described the ups and downs of physical symptoms during treatment. Participants often discussed the unanticipated nature of treatment effects. Among the physical symptoms experienced, fatigue and nausea were the most frequently described. Participants described experiencing nausea and fatigue and its impact on their ability to engage socially with others and to maintain their stamina during lengthy treatments and hospitalizations. Participants emphasize feelings of frustration with their lack of energy during treatment. One participant shares how *“You know you're feeling down and frustrated, nauseous, fatigue, and then the tiredness come in when you're talking with people that are coming to see you...”* (P04, age 24, M, Acute lymphoblastic leukemia). Another participant describes how, *“...it's not that I don't want to keep fighting it's just I'm exhausted, it's been since October, it's almost gonna be a year so umm I'm just kind of like I'm exhausted and my body's tired”* (P05, age 25, M, Testicular cancer). Participants also describe a heightened awareness of physical sensations in their body, such as cramping, numbness, and lightheadedness, and associated treatment factors, such as their hemoglobin and their platelet counts.

Participants share strategies that they have identified to help in managing their physical symptoms, such as bringing aromatherapy to chemotherapy and making a music



playlist that is exactly the length of the radiation session. Participants recount meaningfully gestures from their loved ones that help them with managing their physical symptoms, such as “...*buying me food when I’m nauseous and like the only thing I can eat is a burger, they’ll go and get me a burger...*”(P10, age 22, F, Acute lymphoblastic leukemia). Participants emphasize the critical importance of keeping their medical team updated about their physical symptoms, describing to “...*let your doctors know about everything, EVERYTHING, doesn’t matter what it is*” (P12, age 23, M, Acute myeloid leukemia).

### **Coping Strategies**

The next theme that emerged was coping strategies. The key sub-themes that emerged in regards to coping strategies were “Keep busy” and “Keep a positive vibe”. Participants often shared their coping strategies when discussing what they would recommend as helpful to other young adult cancer patients. Asking questions in the context of what they would recommend as helpful to their peers appears to be effective in fostering dialogue about coping strategies. The key sub-themes that emerged about coping strategies are to “keep busy” and “keep a positive vibe”. Participants consistently emphasize keeping busy and staying active throughout treatment. Participants discuss trying to be open to relying on their support system as needed throughout treatment and surrounding themselves with people who can help them in “keeping a positive vibe”. Some participants acknowledge a sense of social isolation despite being physically surrounded by people during treatment. Some participants describe keeping faith, and refer to certain moments in their treatment process as “blessings” or “signs”. The key sub-themes of “Keep busy” and “Keep a positive vibe” will be discussed.

**Keep busy.** All participants emphasized keeping busy and being distracted throughout treatment. During hospitalizations, participants emphasize trying to spend time outside of their rooms, such as near the main hospital fountain or the cafeteria. A couple of

participants even discussed meeting other young adult cancer patients and going on walks together around the hospital. However, some participants described being isolated from patients their own age.

Participants recommended continued involvement in social activities as much as possible throughout treatment. One participant describes how *“I did my best to continue living life as it was...I still went to you know prom my senior year and I still walked in grad...”* (P03, age 21, M, Acute lymphoblastic leukemia). Some participants even tried new recreational activities during treatment, such as creative writing and contemporary dance. Participants discuss utilizing multiple distraction strategies, such as listening to music, watching television and movies, reading or listening to audiobooks, and browsing blogs and funny websites. One participant notes that, *“If you find the right thing, it'll distract you from the fact that you're in the hospital or that you have this disease, it'll even distract you from having nausea”* (P12, age 23, M, Acute myeloid leukemia). Another participant describes how *“...sometimes like I've watched this movie like 30 times already (laughter) but would you rather be watching this and overanalyzing the movie or overanalyzing everything that's going on...”* (P05, age 25, M, Testicular cancer).

**Keep a Positive Vibe.** Staying active and busy seems to foster the ability to keep a positive mentality during treatment. Participants emphasize that maintaining a positive attitude during treatment keeps them going. Participants acknowledge the mind-body connection. One participant shares how in order to survive *“You have to be very strong mentally and you have to be as strong as you can be physically”* (P12 age 23, M, Acute myeloid leukemia). Some participants describe a sense of psychological denial about being sick to foster their coping. One participant recommends, *“Just to stay positive you know, try to stay active, try to be out and think that you're not sick or say that you're not sick...”* (P04, age 24, M, Acute lymphoblastic leukemia). Another participant shared a photo of

himself flexing his arm muscles on the day that he was diagnosed and describes how during treatment he told his friends that, “*Cancer got me, but cancer never had me*” (P07, age 24, M, Acute lymphoblastic leukemia).

Participants acknowledge needing to time and space to express their stress and their grief. One participant describes, “*Sometimes you get frustrated but it's ok to cry as long as you get back to it. Keep fighting the good fight*” (P05, age 25, M, Testicular cancer). Another participant shares that “*...sometimes being ok with like being mad and knowing that a breakdown may happen and you need to like scream and kick for a while*” (P10, age 22, F, Acute lymphoblastic leukemia).

### **Support Resources**

The next theme that emerged was Support Resources. The key sub-theme that emerged in regards to support resources was “Support needs change over time”. Among study participants, there was a wide range of involvement in cancer support resources, from never accessed any support resources, to tried it once or twice, to ongoing involvement in multiple activities. Participants shared systems barriers, such as limited young adult cancer support resources in certain geographic areas and complicated eligibility criteria, and personal barriers, such as social anxiety and social stigma, when discussing if they accessed support resources. Age appropriate desires to be treated the same by their peers and to maintain their sense of identity independent of their cancer diagnosis seem to strongly reduce interest in accessing cancer support resources. During follow-up interviews, some participants who did not feel comfortable, interested, and/or able to participate in support resources during treatment became involved in support resources relevant to their psychosocial needs post-treatment. Others describe “taking a break” from the cancer community post-treatment. The key sub-theme that emerged regarding support resources is “Support needs change”. Even among young adults of the same age and gender with the

same type of cancer diagnosis, there is not a “one-size fits all” approach that can be applied. The key sub-theme of “Support needs change over time” will be discussed.

**Support Needs Change Over Time.** When comparing perspectives about participation in support resources across study interviews at both time points, interest and involvement in support resources can shift greatly depending upon medical needs and psychosocial circumstances. One participant describes the complexities of matching psychosocial needs and preferences with cancer support programming in detail, saying “...cancer is different for everybody, it's kind of the tough part...and there's also the degree of severity...and what exactly your age is and what other life circumstances you may have...” (P11, age 19, M, Rhabdomyosarcoma). Among participants who did not access support resources, they usually perceived that they did not need it and/or that they would not have benefited from it. Other participants described feeling too overwhelmed and exhausted during treatment to locate and access support resources.

Some participants describe that peer-to-peer cancer support programming clashes with their identity, noting “*I don't like being defined by my cancer and so I don't really, it just feels weird to have a relationship built only on that...*” (P13, age 22, F, Non-Hodgkin's lymphoma). Another participant describes at the beginning of her treatment being introduced to another patient who was her same age and had the same cancer diagnosis who had just completed treatment. Even though this patient was her same age and had the same cancer diagnosis, she perceived that the other patient had experienced much fewer treatment complications. The patient describes how much she struggled during the first two cycles of chemotherapy and how she felt at that time meeting the patient who had just recently completed treatment, “...my ass was given to me, and this girl I was asking her experience, and like do you have a PIC port? ...and she was like WHAT? What are these things? ...and she was the same age as I was, and I was like thank you, goodbye! I deal with this by

*myself...*” (P01, age 19, F, Hodgkin’s lymphoma). Another participant describes hearing about other young adult cancer patients that he has met during treatment who have passed away or are doing worse and how it scares him and makes him worry more about his own treatment and prognosis. He shares that “...*it would bring me down just hearing about it, you know, someone's at the hospital cause of this, so then I started worrying myself about what I'm doing wrong, or what I'm doing that they're doing*” (P04, age 24, M, Acute lymphoblastic leukemia). These experiences speak to the critical importance of the timing of facilitating peer introductions, as well as consideration of differences in treatment effects.

Other participants describe challenges with not meeting the eligibility criteria for resources, the application process being too much of a burden, or scheduling conflicts such as groups that have recurring meetings that conflict with the timing of treatments. Some participants describe accessing web-based support resources, such as Facebook groups, but others prefer in-person opportunities. One participant described how “...*you can look up YouTube videos of people who have gone through it, and like it's helpful but it's just not really the same*” (P08, age 19, F, Hodgkin’s lymphoma). Especially among young adults, they are usually caught between pediatric and adult support resources. One participant shares how challenging it feels, “...*you're now being shifted to all of these different resources and you're dealing with this with other adults but you're not totally an adult so that's I think different, that's what makes this different, but you're not totally a kid anymore either...*” (P11, age 19, M, Rhabdomyosarcoma). Some participants describe a decrease in the availability of resources from during treatment to post-treatment. One participant shares how “*Like when you have cancer, there's a ton of resources but once you're done, it's like everyone forgets that you had cancer and you don't know how, you don't know what to do*” (P02, age 22, F, Wilms Tumor).

In a follow-up interview, one participant describes seeing her social worker at a follow-up medical visit. She shares that her social worker offered her more resources even though she felt she already had too much on her plate. It seems that the patient perceived that accessing support resources would become an additional burden. Other participants describe finally being able to access support resources after the completion of treatment. One participant shares how much he loved and appreciated attending a testicular cancer summit in which he finally got to meet other young people with testicular cancer for the first time. He describes how “...*I didn't, you know, meet anybody until I went to this conference that actually had testicular cancer so it was, it was really great to hear their stories and to hear how they went through and how they've persevered...*” (P09, age 25, M, Testicular cancer). Some participants seek leadership in cancer support communities post-treatment, such as joining the hospital young adult cancer advisory council or starting a local support group at their neighborhood library.

### **Post-Treatment Experiences**

The next theme that emerged was Post-Treatment Experiences. In follow-up interviews, participants shared both new experiences and achievements and ongoing medical and psychosocial challenges. The key sub-themes that emerged in regards to post-treatment experiences were “Trying new things to cope with losses” and “Managing expectations with realities”. Participants are continuously managing their expectations with the realities of life post-treatment. Age appropriate young adult transitions, such as finding a job, making new friendships in college, and moving in with a romantic partner become more stressful when complicated by ongoing physical and psychological treatment effects. One participant describes how, “...*I feel a lot older than I should, like I feel like I'm trying to make decisions that 30 year olds would make, as opposed to a 22 year old girl who just got out of college*” (P02, age 22, F, Wilms Tumor). Some participants describe a heightened

sense of awareness, meaning, purpose, and gratitude in their lives. One participant shares that *“I kind of took inventory of my life and you know what I wanted to do umm while I was going through treatment and then was able to use you know that motivation, that analysis from what I thought I could be doing, to actually put in practice...”* (P09, age 25, M, Testicular cancer). Another participant shares her newfound appreciation, such as *“...like not being constipated is like a blessing that people just don't know about”* (P06, age 27, F, Ewing sarcoma). There is a sense of urgency about returning to “normalcy”. One participant describes how, *“You know like I wanna get back in shape, I wanna get to the same person I was 5 years ago, I wanna be that same person again you know, and not say, not blame cancer about what I can't accomplish or anything like that”* (P04, age 24, M, Acute lymphoblastic leukemia). The key sub-themes of “Trying new things to cope with losses” and “Managing expectations with realities” will be discussed.

**Trying New Things to Cope with Losses.** Participants consistently emphasize looking ahead to the future and trying new things. One participant shares how *“...you feel better if you're exposed to newer things and, and newer things sort of give you new insights and new experiences that can help you perhaps deal with the recovery...”* (P11, age 19, M, Rhabdomyosarcoma). Some participants take trips or participate in new recreational activities upon treatment completion. One participant describes his feelings after completing treatment and taking a celebratory trip with his family, saying *“I think it was important for not just me but for the whole family, it was like a big exhale...it was another thing to like turn that page”* (P03, age 21, M, Acute lymphoblastic leukemia). One participant who went on a kayaking trip with young adult cancer survivors after treatment describes how great it felt to meet other young adult cancer survivors, saying *“...hey, there's other people out there that are also thriving and living and moving on with life”* (P06, age 27, F, Ewing sarcoma). Other participants continue to struggle with severe physical effects

post-treatment and are unable to travel and/or engage in recreational activities and are awaiting further medical procedures. One participant who continues to suffer from post-transplant medical complications emphasizes, “*Don't think about getting back to where you were. Don't think about the big picture. Just think about what you're doing right then, and what you need to do tomorrow*” (P12, age 23, M, Acute myeloid leukemia). His suggestions support the application of mindfulness practice in fostering present moment awareness.

**Managing Expectations with Realities.** Participants are navigating the stress, uncertainty, and excitement of young adulthood throughout their cancer journey. In follow-up interviews, when discussing reintegrating socially and professionally, there is usually a mismatch between how participants imagined things would be after completing treatment and the reality of the challenges they continue to face in their daily lives. One participant describes how she moved back to college immediately after completing treatment but then had to move back home after a couple weeks due to severe anxiety and panic attacks. She shares how “*I think I set my expectations a little bit too high as well... like the day I finish radiation is like the day I'm like completely done with treatment and I'll feel 100% better, it's just not realistic...*” (P08, age 19, F, Hodgkin’s lymphoma). She describes wishing that she had been provided with more information when she was finishing treatment to help anticipate the social challenges of returning to college.

Participants who were athletes prior to their cancer diagnosis identify this as a critical part of their identity and describe the mental anguish experienced as a result of the loss of their physical abilities during cancer treatment. One participant who suffered a stroke during his leukemia treatment shares how “*I have always been an athlete, and basketball is my passion and my hobby...I don't know if I'm ever going to play basketball again to the extent that I did before cancer and before my stroke, and that breaks my heart, nothing makes me feel more alive than playing hoops...*” (P03, age 21, M, Acute



lymphoblastic leukemia). Another participant who was a competitive skier prior to her cancer diagnosis has struggled with the loss of physical activity and loss of muscle mass during cancer treatment. In follow-up interviews, participants who have experienced improvement in their physical symptoms post-treatment seek opportunities to re-engage in physical activities and to re-establish this critical part of their identity.

Other participants describe ongoing struggles with finding employment, maintaining health insurance, and managing physical symptoms. One participant describes her challenges with maintaining health insurance coverage, saying “...*I just graduated college, I don't have a job yet, I can't be under my parents health insurance so I'm trying to figure out what to do, so right now I'm on Medi-Cal but once I get a job I'll switch to whatever health insurance they provide*” (P02, age 22, F, Wilms Tumor). Participants shared continued feelings of awkwardness and uncertainty about disclosure of their cancer diagnosis with their peers. One participant who had to move home from college for treatment describes concerns about the transition back to living with her peers again at college and being asked questions about her treatment, saying “...*it's like definitely very emotional and it's also kind of like very new, like I don't think that I've really processed everything yet...*” (P13, age 22, F, Non-Hodgkin's lymphoma). Some participants describe enhanced perspective about managing everyday stressors and disappointments, such as job loss, saying “*I mean I think it's like you know the worst that can possibly happen to you is experiencing near death...it's like what could possibly get worse than that...there'll be more jobs...*” (P06, age 27, F, Ewing sarcoma). Potential challenges with navigating post-treatment transitions, such as returning to college, discussing their cancer diagnosis and treatment with peers, finding employment, managing ongoing health concerns and follow-up medical care, and maintaining health insurance should be discussed with patients early and often in the care trajectory.

## **Discussion**

Study interviews were filled with a variety of emotions and reactions including but not limited to hope, fear, loss, growth excitement, worry and anticipation about the future. Study interviews became an opportunity for participants to share their narratives. Participants usually recounted when they were diagnosed with cancer, juxtaposing their lives before and after cancer. Consistent with previous research examining the online narratives of young adult cancer patients (Kim & Gillham, 2013), participants often described feeling contradictory emotions after cancer treatment. Participants frequently used humor to cope with losses and ongoing medical challenges. Feelings of social connectedness and social isolation were frequently discussed in the context of their treatment process, such as a sibling being at the hospital with them during procedures, a parent taking notes during medical visits, or being separated from friends and family during hospitalizations. While the strength of some social ties becomes stronger during treatment, they may suffer the loss of other social ties. There is simultaneous growth and loss in their social networks throughout the care trajectory.

There was a great deal of variation in regards to participant interest and involvement in psychosocial support resources, but there was consistency in regards to their desires to be treated the same by their peers and to stay busy and active during treatment. Participants describe watching movies and Netflix shows, listening to music and podcasts, and reading books during hospitalizations. These activities may present opportunities to offer psychoeducation, therapeutic support, and to connect with other young adult cancer patients. The timing of when support resources are offered appears to be critical, such that if a peer survivor is introduced too soon, too late, or during a medically stressful time in the care trajectory, it may increase the likelihood that it will not be well received. Rapport must be established with the patient prior to discussing potential interest in accessing support

resources and to determine appropriate matching of support resources offered. Resources should be accessible, flexible, and age-appropriate.

Engagement with the healthcare team is critical in fostering hope and treatment adherence. From the very first encounter, participants describe assessing provider engagement and respect, such as through eye contact (with them versus their parent). Study participants frequently discussed communication with their healthcare team. Participants described encounters in which they felt the healthcare team could have been more empathic, hopeful, and clear in their communication, as well as interactions in which they felt members of the healthcare team provided supportive and thoughtful information that helped improve their understanding of their treatment.

In regards to informational support, there seems to be a direct association between information received and self-efficacy for managing their illness. Participants who feel less informed about their diagnosis and treatment also feel less in control and therefore less confident in their ability to manage their illness and to make treatment decisions. Participants need to be provided with clear information and supportive resources to help them anticipate and manage medical and psychosocial challenges throughout the care trajectory. Consistent with research by Zebrack and colleagues (2010), providers should communicate information directly and honestly, without condescension or patronization, while being cognizant of AYAs developing cognitive capacities and how much information can be comprehended and absorbed.

There was a palpable sense of urgency about completing treatment and returning to “normalcy”. The severity of physical treatment effects appears to moderate social re-integration post-treatment. Participants who experience more severe physical treatment effects also describe more challenges with social re-integration. These participants would benefit from additional support in regards to coping with changes in body image and social

stigma. Additionally, patients who are younger at the age of cancer diagnosis may benefit from more intensive support and assistance in navigating social situations post-treatment, such as returning to college. Participants are eager to engage in new experiences post-treatment, and this appears to be an opportune time to present therapeutic recreational opportunities to connect with other young adult cancer survivors.

## Chapter 6: Quantitative Findings

### Introduction

This chapter will discuss results from the Patient-Reported Outcomes Measurement Information Systems (PROMIS) measures of social functioning completed by study participants within approximately six months of the completion of active treatment and again three months later. Study participants ( $N=13$ ; ages 17-25 at the time of cancer diagnosis; ages 19-27 at the time of study participation) completed the supplemental self-report questionnaires upon conclusion of the qualitative interview. At the initial study visit, participants completed the paper questionnaires in-person at the time of study participation ( $n=11$ ) or electronically after the visit via Qualtrics survey ( $n=2$ ). One participant died in the interim between the initial visit and the 3-month follow-up study visit. The majority of study participants completed the follow-up questionnaires electronically via Qualtrics survey ( $n=9$ ) and three participants completed the follow-up questionnaires on paper. Flexibility in regards to participant choice of questionnaire format (electronic or paper) helped to foster questionnaire completion.

### Time 1

Chronbach's alpha analysis was conducted to assess the internal consistency of the study measures. All four measures demonstrated good internal consistency: PROMIS Ability to Participate in Social Roles and Activities ( $\alpha = .92$ ), PROMIS Social Isolation ( $\alpha = .94$ ), PROMIS Satisfaction with Social Roles and Activities ( $\alpha = .95$ ), and PROMIS Self-Efficacy for Managing Social Interactions ( $\alpha = .80$ ).

All study participants ( $N=13$ ) were administered Time 1 questionnaires. One participant (P01) had greater than 20% missing data on the Time 1 questionnaires and was excluded from Time 1 analyses. All other study participants ( $n=12$ ) answered all items on all four questionnaires. Participant T-scores for all four measures were received from the

HealthMeasures Scoring Service and were categorized according to the T-score ranges (see Table 4, p. 76). Participant T-scores were used to calculate scale descriptives (see Table 4, p. 76). The self-efficacy for managing social interactions measure had the lowest mean ( $M=46.33$ ,  $SD=7.93$ ), followed by ability to participate in social roles and activities ( $M=47.89$ ,  $SD=6.60$ ), satisfaction with social roles and responsibilities ( $M=49.18$ ,  $SD=8.81$ ), and social isolation ( $M=49.41$ ,  $SD=9.06$ ). On the self-efficacy for managing social interactions measure, there was the greatest impairment among participants, with 58.4% of participants experiencing mild ( $n=5$ ) or moderate ( $n=2$ ) impairment in this domain. On the ability to participate in social roles and activities, the majority of participants ( $n=9$ ) had T-scores within normal limits, but three participants had T-scores in the moderate impairment range. On the satisfaction with social roles and responsibilities scale, the majority of participants had T-scores that were within normal limits ( $n=7$ ), while three participants had T-scores in the moderate impairment range, and two participants had T-scores in the mild impairment range. On the social isolation scale, the majority of study participants had T-scores that were within normal limits ( $n=10$ ), one participant had a T-score in the mild impairment range, and another participant had a T-score in the moderate impairment range.

## **Time 2**

One study participant passed away in the interim between Time 1 and Time 2. The remaining study participants ( $n=12$ ) were emailed the same four questionnaires via Qualtrics survey at Time 2. One participant (P01) skipped a few items on the follow-up questionnaires, but since she answered at least 4 items (out of 8) on every questionnaire, her data could be included. All other participants answered all items on all four questionnaires. A Chronbach's alpha analysis was conducted to assess the internal consistency of the study measures at Time 2. All measures demonstrated good internal

consistency: PROMIS Ability to Participate in Social Roles and Activities ( $\alpha = .95$ ), PROMIS Social Isolation ( $\alpha = .88$ ), PROMIS Satisfaction with Social Roles and Activities ( $\alpha = .95$ ), and PROMIS Self-Efficacy for Managing Social Interactions ( $\alpha = .82$ ).

Participant T-scores were used to calculate scale descriptives (see Table 4, p. 76). The self-efficacy for managing social interactions measure had the lowest mean ( $M=47.22$ ,  $SD=7.78$ ), followed by ability to participate in social roles and activities ( $M=48.53$ ,  $SD=6.81$ ), social isolation ( $M=49.06$ ,  $SD=5.49$ ), and satisfaction with social roles and responsibilities ( $M=51.03$ ,  $SD=7.52$ ). Participant T-scores for all four measures were received from the HealthMeasures Scoring Service and were categorized according to the score ranges (see Table 4, p. 76). On the self-efficacy for managing social interactions, the majority of study participants had T-scores within normal limits ( $n=8$ ), three participants had T-scores that were in the moderate impairment range, and one participant had a T-score in the mild impairment range. On the ability to participate in social roles and activities measure, the majority of participants ( $n=8$ ) had T-scores within normal limits, but a couple of participants had T-scores that were in the mild impairment range, and a couple of participants had T-scores that were in the moderate impairment range. On the social isolation measure, the majority of participants had T-scores that were within normal limits ( $n=10$ ) and two participants had T-scores that were in the mild impairment range. On the satisfaction with social roles and responsibilities measure, the majority of study participants had scores that were within normal limits ( $n=9$ ), a couple of participants had T-scores that were in the mild impairment range, and one participant had a T-score that was in the moderate impairment range.

Table 4  
*Self-Report Measures Descriptives*

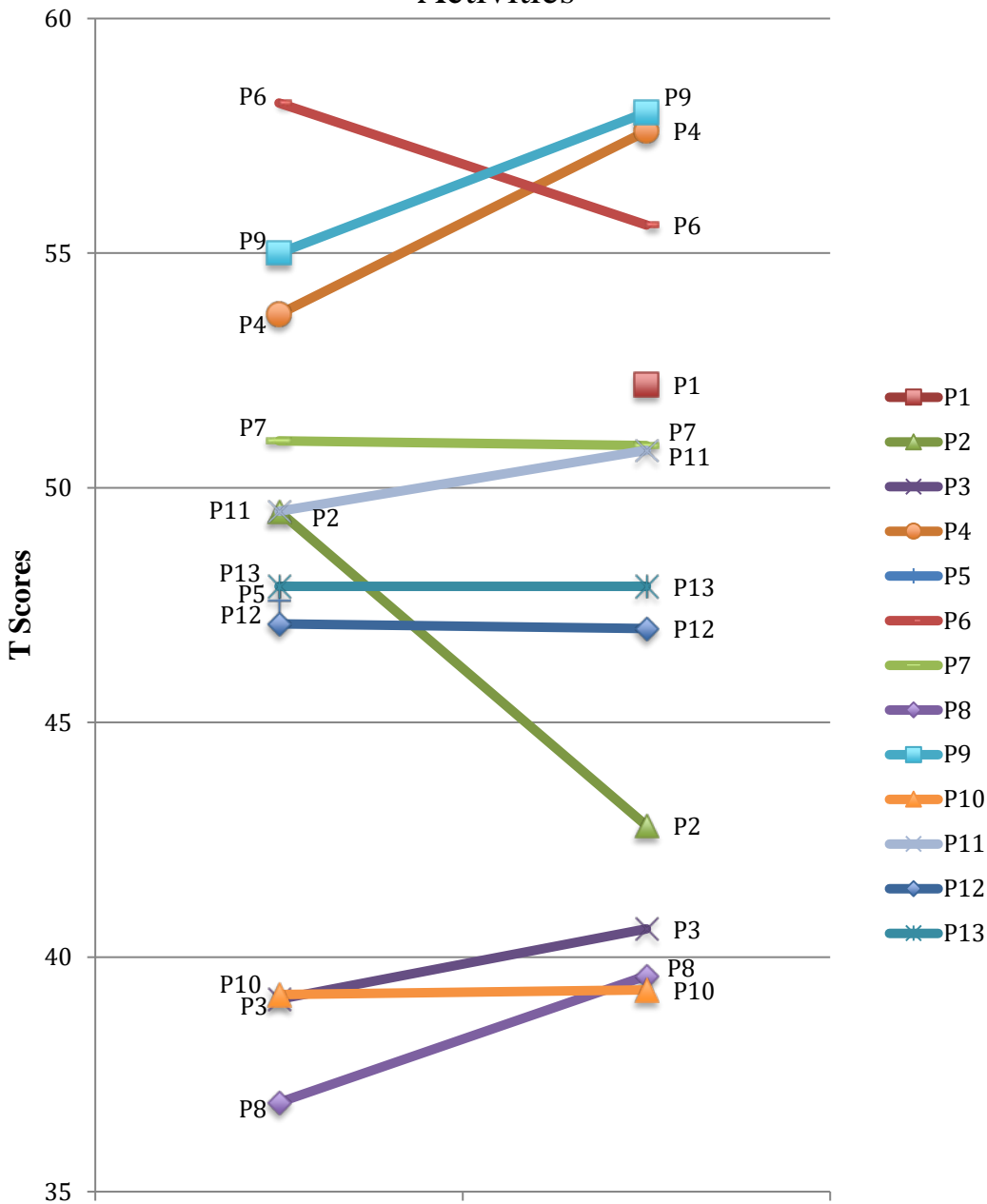
	Time 1 (n=12)			Time 2 (n=12)		
	M (SD)	Range	n (%)	M (SD)	Range	n (%)
<b>Self-Efficacy for Managing Social Interactions</b>	46.33 (7.93)	34.60 – 59.80		47.22 (7.78)	36.00 – 59.80	
Normal			5 (41.7)			8 (66.7)
Mild			5 (41.7)			1 (8.3)
Moderate			2 (16.7)			3 (25.0)
<b>Satisfaction with Social Roles &amp; Activities</b>	49.18 (8.81)	36.60 – 60.70		51.03 (7.52)	38.00 – 65.10	
Normal			7 (58.3)			9 (75.0)
Mild			2 (16.7)			2 (16.7)
Moderate			3 (25.0)			1 (8.3)
<b>Ability to Participate in Social Roles &amp; Activities</b>	47.89 (6.60)	36.90 – 58.20		48.53 (6.81)	39.30 – 58.00	
Normal			9 (75.0)			8 (66.7)
Mild						2 (16.7)
Moderate			3 (25.0)			2 (16.7)
Severe						
<b>Social Isolation</b>	49.41 (9.06)	34.00 – 64.70		49.06 (5.49)	42.20 – 59.80	
Normal			10 (83.3)			10 (83.3)
Mild			1 (8.3)			2 (16.7)
Moderate			1 (8.3)			



### **Comparison of T-Scores Between Time 1 & Time 2**

Participant T-scores were plotted to help visualize participant T-scores at both time points for each measure (see Figures 2 – 5, p. 78-81). Paired samples t-tests were computed to assess if there were any significant differences between groups in participant T-scores at Time 1 and Time 2. There was not a significant difference between groups in participant T-scores at Time 1 and Time 2 on any of the four measures. There was not a significant difference between groups in participant T-scores for self-efficacy for managing social interactions at Time 1 and Time 2;  $t(10) = -.492, p = .633$ . There was not a significant difference between groups in participant T-scores for participation in social activities at Time 1 and Time 2;  $t(10) = -.308, p = .764$ . There was not a significant difference between groups in participant T-scores for social isolation at Time 1 and Time 2;  $t(10) = .943, p = .368$ . There was not a significant difference between groups in participant T-scores for satisfaction with social activities at Time 1 and Time 2;  $t(10) = -.733, p = .480$ .

Figure 2: Participation in Social Roles & Activities



**Score Ranges**  
 45.0 – 80.0 (Within Normal Limits)  
 40.0 – 44.9 (Mild Impairment)  
 30.0 – 39.9 (Moderate Impairment)  
 20 – 29.9 (Severe Impairment)

Figure 3: Satisfaction with Social Roles & Activities

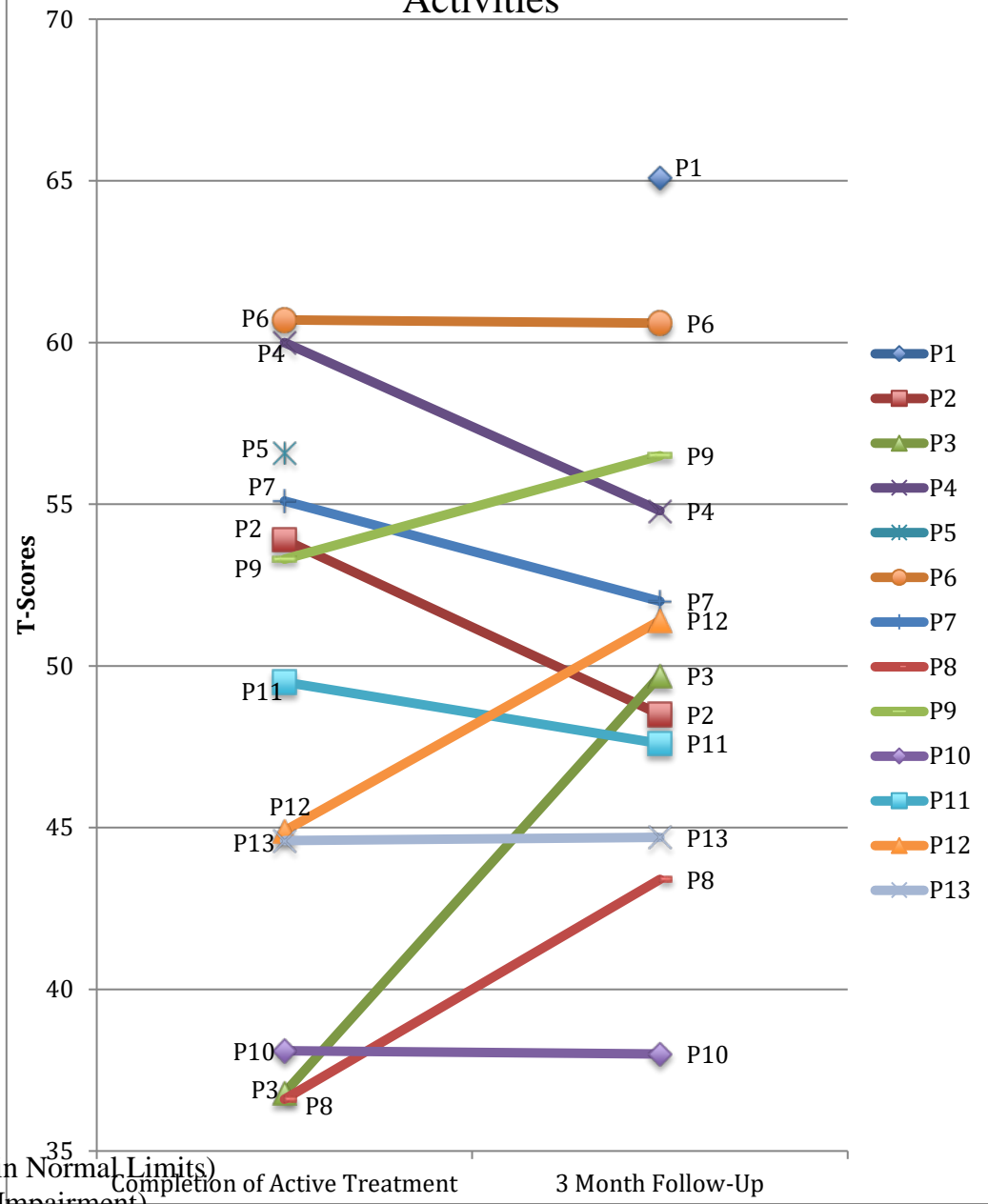


Figure 4: Self-Efficacy for Managing Social Interactions

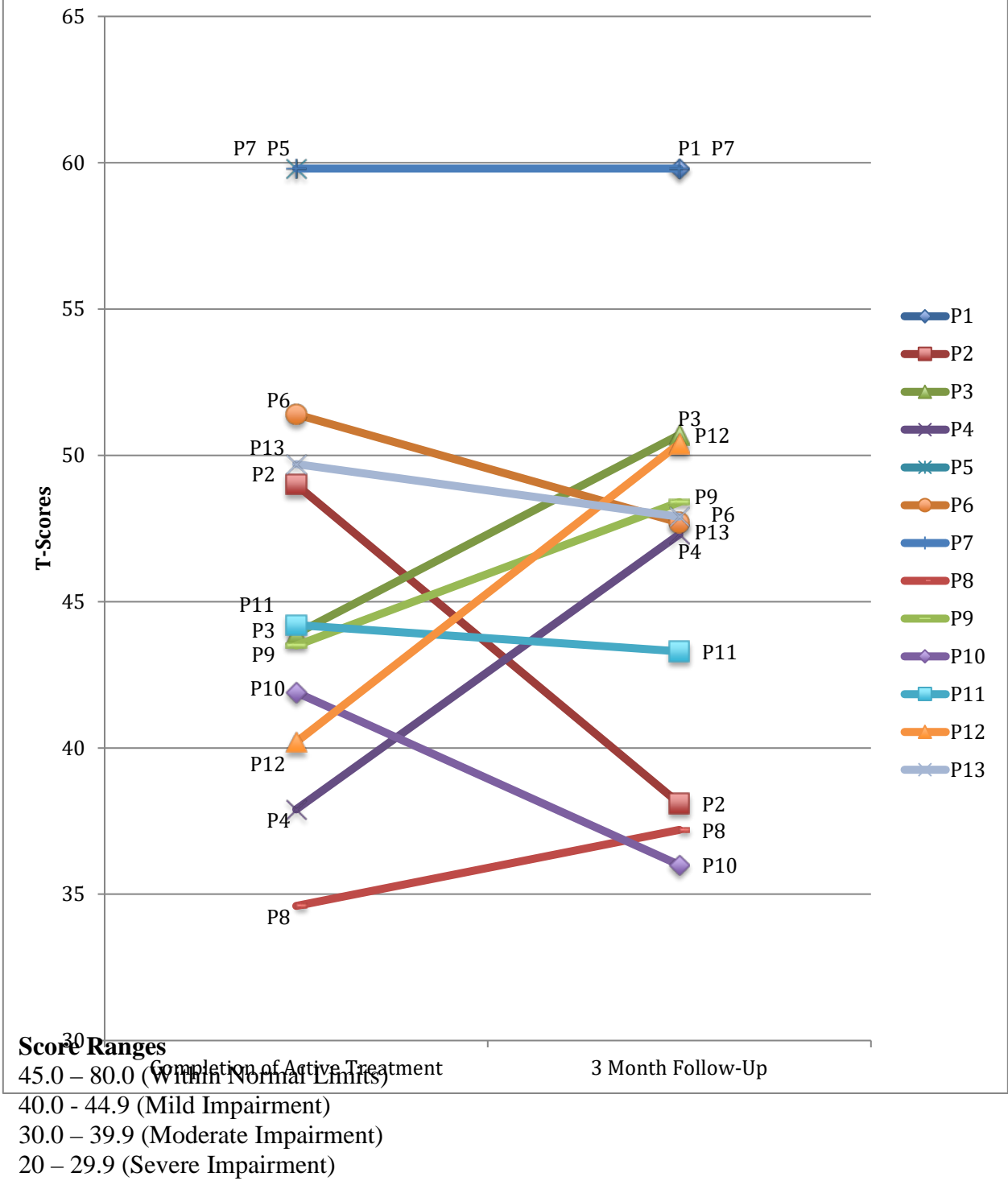
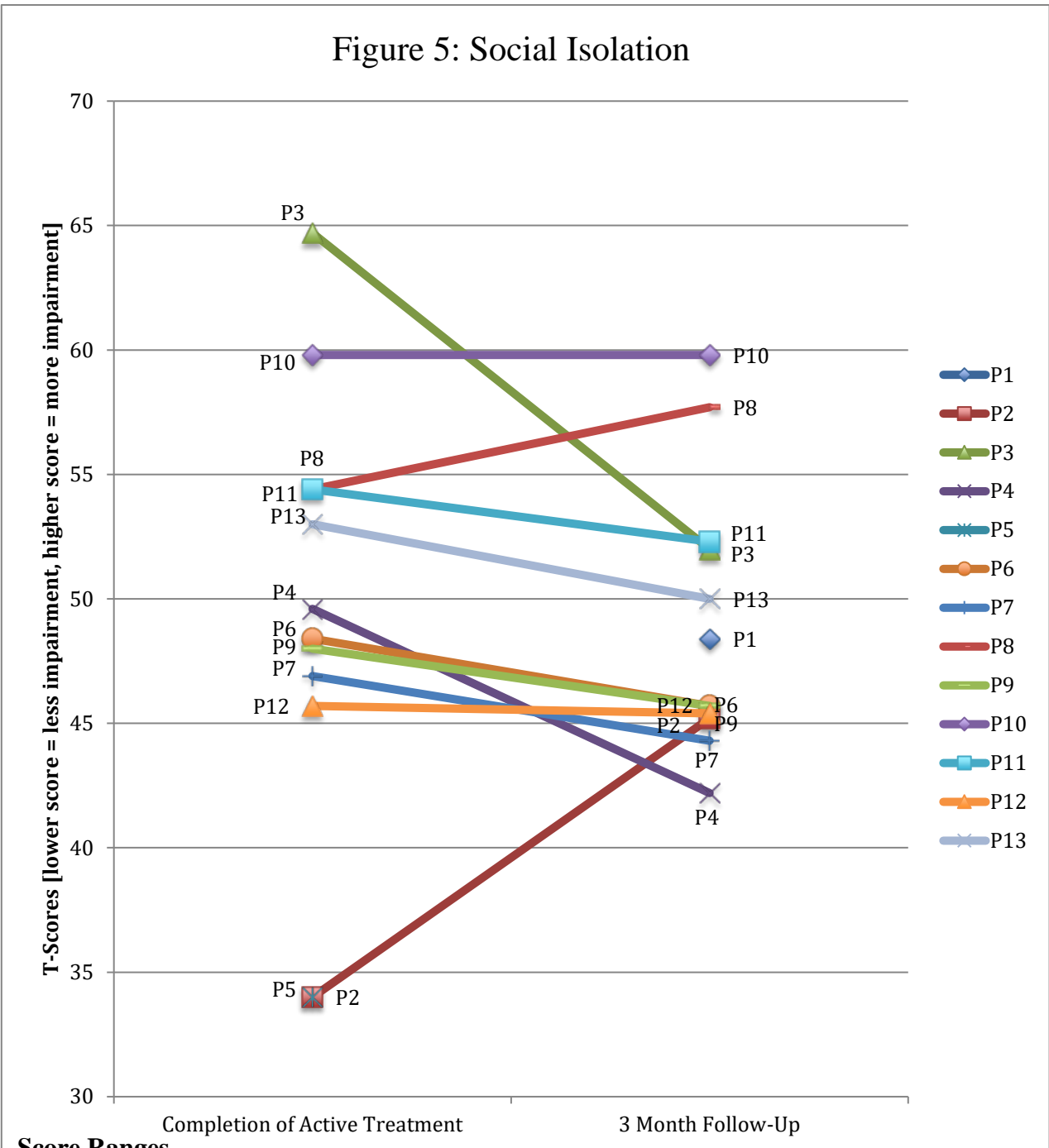


Figure 5: Social Isolation



**Score Ranges**

- 20-54.9 = 0 (Normal)
- 55.0-59.9 = 1 (Mild)
- 60.0-69.9 = 2 (Moderate)
- 70.0-80 = 3 (Severe)

## **Discussion**

On the self-report measures at Time One, there was the greatest impairment among participants on the self-efficacy for managing social interactions, with 58.4% of participants experiencing mild ( $n=5$ ) or moderate ( $n=2$ ) impairment in this domain. There were no statistically significant differences between groups in participant T-scores at Time One and Time Two on any of the four measures. There were three participants (P03, P08, P10) who experienced mild or moderate impairment across multiple domains of social functioning. These participants were the youngest at the time of cancer diagnosis in this sample (P03: Age 17, P08: Age 18, and P10: first diagnosed with cancer as an adolescent and currently being treated for cancer recurrence at age 20). Two of these participants (P03 & P10) were treated for acute lymphoblastic leukemia. One of these participants (P08) was treated for Hodgkin's lymphoma. P08 traveled to receive cancer treatment and experienced isolation from her friends, family, and other young adult cancer patients during her treatment. P08 also described unaddressed mental health concerns during and post-treatment. A couple of participants suffered severe physical treatment effects. P03 suffered a stroke during treatment and P10 suffered from arteriovenous malformation (AVM).

Additional contextual information provided by study participants during the qualitative interviews will be discussed in the integration of findings in Chapter 7. Findings suggest that young adult survivors who experience more severe physical treatment effects, who have unaddressed mental health needs, and who are younger at the time of cancer diagnosis may experience more impairment in social functioning post-treatment. Findings support screening for the social functioning of AYAs early and often in the care trajectory

to identify patients who may need additional support and to provide referrals to age-appropriate resources as needed.

## **Chapter 7: Discussion**

### **Introduction**

This chapter will discuss and integrate the qualitative and quantitative study findings. Using a concurrent embedded design (Creswell & Plano Clark, 2011), qualitative interviews were the primary data source, with supplemental self-report measures of social functioning collected from study participants at both time points. In a concurrent embedded design, the data is collected at the same time, but one method is embedded in the other (e.g. the self-report measures data is embedded in the qualitative interview data). Findings from the supplemental self-report measures data were interpreted using the contextual information from the interview data. This chapter will also include discussion of the study strengths and limitations.

### **Integration of Findings**

Key themes from study interviews and findings from the self-report measures of social functioning highlight the complexities of the psychosocial, developmental, and medical needs of young adult cancer survivors. During the transition from active treatment to survivorship care young adult cancer survivors are facing the opportunities and challenges of social reintegration as they manage ongoing treatment effects. The developmental tasks of young adulthood, such as identity exploration and developing self-sufficiency (Arnett, 1998), are disrupted by a cancer diagnosis. Consistent with recent systematic review of the needs of young adult cancer survivors during the end-of-treatment and early post-treatment (Walker & Marcus Lewis, 2016), participants may struggle with feeling unsupported and unprepared for survivorship. There is often a mismatch between expectations about psychosocial and physical functioning at the end of treatment and the realities of the ongoing challenges experienced post-treatment.



These complex multi-layered stressors can often be difficult to capture in a questionnaire. Young adults may also perceive some of the questionnaire constructs differently, such as feeling like they may relate to their peers differently since being diagnosed with cancer versus a sense of social isolation. Additionally, participants may have T-scores that are within “normal” range on generalized measures of social functioning, but as illuminated through the qualitative interviews, they may still be experiencing more nuanced challenges specific to their cancer diagnosis and treatment not captured on generalized measures of social functioning, such as concerns about disclosure of their cancer diagnosis to their peers and changes in their social identity and body image.

During study interviews, patients receiving treatment for leukemia often described more severe medical and psychosocial stressors than their peers being treated for other forms of cancer, including prolonged hospitalizations, more severe physical symptoms, and more limited opportunities for social engagement with their peers. Additionally, patients who had to relocate to receive their cancer treatment described feeling more isolated from their friends and family. Participants who were receiving treatment at the children’s hospital often mentioned more opportunities to feel supported by staff, such as through small gestures of kindness, and a friendlier and warmer physical environment. Consistent with a recent literature review examining the experiences of AYAs treated in the adult setting (Marshall, Grinyer, & Limmer, 2018), AYAs treated in the adult setting tend to feel more isolated and in need of more inclusive facilities with leisure space and opportunities to connect with their peers.

Study findings suggest that young adult survivors frequently experience reduced self-efficacy for managing social interactions during the transition from active treatment to survivorship care. Losses experienced during treatment and changes in social identity cause greater uncertainty about social re-integration with peers. On the self-report

measures at Time One, there was the greatest impairment among participants on the self-efficacy for managing social interactions, with 58.4% of participants experiencing mild ( $n=5$ ) or moderate ( $n=2$ ) impairment in this domain. There were no statistically significant differences between groups in participant T-scores at Time One and Time Two on any of the self-report measures. There were three participants (P03, P08, P10) who experienced mild or moderate impairment in multiple domains of social functioning. These patients were the youngest at the time of cancer diagnosis in this sample (P03: Age 17, P08: Age 18, and P10: first diagnosed with cancer as an adolescent and currently being treated for cancer recurrence at age 20). Two of these patients (P03 & P10) were being treated for acute lymphoblastic leukemia. One of these patients (P08) was treated for Hodgkin's lymphoma.

As informed by the qualitative interview data, two of these patients (P03 & P08) had been competitive athletes prior to their cancer diagnosis and suffered the loss of involvement in basketball and skiing during treatment. One of these patients (P08) traveled to receive her cancer treatment and experienced isolation from her friends, family, and other young adult cancer patients during her treatment. She also described unaddressed mental health concerns during and post-treatment. A couple of participants suffered severe physical treatment effects. P03 suffered a stroke during treatment and P10 suffered from arteriovenous malformation (AVM).

Research examining the social functioning of AYAs over time highlights the critical importance of symptom management and psychosocial interventions in the first year post-diagnosis, noting that improvements in social functioning usually take place within the first year post-diagnosis and that on average there are no significant additional improvements between 12 and 24 months (Husson, Zebrack, Aguilar, Hayes-Lattin, & Cole, 2017). In the 3-month follow-up interview, P03 had begun to experience

improvements in his physical functioning through ongoing participation in physical therapy and he had also become more involved with his peers again and was getting ready to return to college. These improvements are reflected in the relative improvements in his social functioning scores at Time Two. In the follow-up interview with P08, she had tried to return to college post-treatment but had to return home after a couple weeks due to severe anxiety and panic attacks. In the follow-up interview with P10, she continued to struggle with arteriovenous malformation and was awaiting surgery.

Taken together, these findings suggest that young adult survivors who experience more severe physical treatment effects, who have unaddressed mental health needs, and who are younger at the time of cancer diagnosis may experience more impairment in social functioning post-treatment. Young adult cancer patients ages 20-29 are significantly less likely to use professional mental health than teens and older patients 30 to 39 years of age (Coccia et al., 2018). Anxiety and depression can impact quality of life and survival outcomes among AYAs with cancer, such as potential non-adherence with treatment, increase in physical pain, and higher disease morbidity (Lauer, 2015). Mental health concerns should be screened for and treated in tandem with medical concerns throughout treatment and beyond. Post-treatment symptom management and distress management may help to decrease negative impacts of cancer and increase positive impacts of cancer (Husson & Zebrack, 2016).

Consistent with previous research exploring the benefits and burdens of cancer among AYAs (Straehla et al., 2017), participants identified both benefits, such as enhanced meaning, purpose, and gratitude in their lives, and burdens, such as physical distress. Coping strategies to manage stressors were frequently discussed in the context of what study participants would recommend as helpful to other young adult cancer patients. Participants consistently emphasized keeping busy and staying active throughout

treatment. Participants often described not being able to cope with the psychological effects of treatment until after the completion of active medical treatment. This appears to be adaptive in terms of conserving energy in the mind and body to be able to manage physical symptoms during treatment. One participant (P04, age 24, M, Acute lymphoblastic leukemia) describes in his 3 month follow-up interview, “...*What I did when I was in treatment I always told myself that I wasn't sick, nothing was wrong with me, cause it all comes from the brain you know, it all comes from the mind...*” Another participant (P08, age 19, F, Hodgkin’s lymphoma) contrasts her perceptions of her mental health during treatment versus post treatment in her follow-up interview, describing:

*“I was a little bit blindsided by the like, emotional aspect of it cause I felt that like throughout like chemo and radiation I was like you know, like, pretty like mentally strong, you know there are obviously hard days but I don't think that like I ever felt like completely overwhelmed or just like you know, completely, just like, dealing with anxiety and stuff, I never experienced that...”*

Another participant (P02, Age 22, F, Wilms Tumor) also expresses enhanced awareness post-treatment of the severity of her illness, describing:

*“...now like looking back (sigh), looking back I don't know how I did what I did, but I think, I think a part of it comes down to the fact that when you're in it you don't know how bad it is because you, you progressively get worse and you don't realize all the things that you do to make up for how bad you feel, so I think it's kind of hitting me now like this was actually an ordeal, you know everyone kept telling me it was an ordeal, I didn't believe them until after it was all over.”*

Traditional models of stress and coping, such as the Transactional Model (Lazarus & Folkman, 1984; Lazarus, 1999) that was developed to examine stress, appraisal, and coping primarily in the context of coping with an acute stressor, should be adapted to better

understand how coping processes differ among young adult cancer patients in the context of chronic psychological and medical stressors. Not only the individual's perceptions of their ability to cope with their illness, but also the dynamic interactions between the patient's perceptions and the perceptions of their caregivers, peers, and members of their healthcare team appear to play a critical role in coping processes throughout the cancer care trajectory.

Lack of insurance is consistently associated with greater risk of mortality for AYAs of all ages and with nearly all types of cancer (DeRouen, Parsons, Kent, Pollock, & Keegan, 2017). There was one participant who passed away during this study. He had a diagnosis of testicular cancer, identified as Hispanic, and was uninsured at the time of cancer diagnosis. Testicular cancer is among the six AYA cancer sites with the highest relative survival rates (Howlader et al., 2016) that were found to have the strongest association between health insurance and survival (DeRouen, Parsons, Kent, Pollock, & Keegan, 2017). This suggests that insurance status likely influences not only initial cancer diagnosis and treatment, but also what happens after treatment initiation (DeRouen, Parsons, Kent, Pollock, & Keegan, 2017).

Engaging young adult cancer survivors in psychosocial services can often be challenging. Among study participants, there was a wide range in regards to interest in and involvement with support resources, from never accessed any support resources, to tried it once or twice, to ongoing involvement in multiple activities. Previous research suggests potential barriers and challenges to initiating and sustaining AYA peer support programming such as the diversity of the AYA age range, geographical and financial barriers, a lack of cultural diversity in support group offerings, a lack of awareness and referrals from health care providers, and finding ways to offer support at different phases of the cancer trajectory (Treadgold & Kuperberg, 2010). While some of these challenges

were described by study participants in regards to their lack of involvement in support programming, the biggest barrier to participation in support resources among study participants appears to be age appropriate desires to be treated the same by their peers and to maintain their sense of identity independent of their cancer.

Participants frequently discussed the timing of when support resources were offered in the context of their treatment process. The timing of when support resources are offered appears to be critical, such that if a peer survivor is introduced too soon, too late, or during a medically stressful time in the care trajectory, it may increase the likelihood that it will not be well received and may be perceived as an additional burden. Existing theoretical models, such as the Optimal Matching Model of Stress and Social Support (Cutrona, 1990), which attempt to match the individual's level of need with the support resources offered, are complicated by frequent shifts in physical and social functioning throughout cancer treatment. This suggests the critical importance of building trust and rapport with patients and their caregivers early in the care trajectory in order to individually assess their interests, needs, and preferences and to form the foundation for an ongoing relationship to be able to offer support resources appropriately as their psychosocial and medical needs change. Involvement with support resources during treatment will likely enhance social re-integration post-treatment.

### **Study Strengths & Limitations**

The strengths of this study include the specific time frame of data collection that targeted the transitional period from active treatment to survivorship care, the mixed methods research approach, sample diversity in terms of gender and race/ethnicity, and the inclusion of two data collection time points. The specificity of the data collection time points used in this study is unique and enhances the existing knowledge about the transition

needs of AYA cancer survivors, which is more typically studied using cohort data of AYA survivors spanning a number of years post-treatment. The limitations of this study include that all patients were recruited from an academic medical center, small sample size for the quantitative data, the self-report measures were not developed specifically for young adult cancer patients, all study participants were English speaking, and the study did not include peers or caregivers.

## **Chapter 8: Implications**

### **Introduction**

This chapter will review and discuss the clinical, research, and policy implications of the study findings. Improving the health and psychosocial outcomes of young adult

cancer survivors will involve ongoing research, advocacy, training, interdisciplinary collaboration, and innovation in clinical care. Patient and caregiver feedback should be utilized in all aspects of care delivery, program development, and program evaluation. Social workers are trained with the knowledge and skills to intervene and collaborate at all levels as advocates, researchers, and clinicians (Andrews, Darnell, McBride, & Gehlert, 2013). We can all work together to help ensure that young adult cancer survivors have the resources that they need to “get busy living” (Stupid Cancer, 2016).

### **Clinical Implications**

Every clinical encounter is an opportunity to provide support and to address the unmet needs of patients and their caregivers. Study findings underscore the critical importance of making every effort to help foster AYAs continued involvement in their social and professional lives throughout treatment (Coccia, 2018). Study findings suggest that young adult survivors often experience reduced self-efficacy for managing social interactions during the transition from active treatment to survivorship care. Losses experienced during treatment and changes in social identity cause more uncertainty about social re-integration post-treatment. During this transition, young adult cancer survivors would likely benefit from opportunities to meet with other young adult cancer survivors to discuss how to manage social interactions with their peers post-treatment. Throughout the care trajectory, opportunities to stay involved socially in extracurricular activities with their peers and to participate in developmental milestones should be fostered.

Participants who suffered more severe physical treatment effects, who had unaddressed mental health needs, and who were younger at the age of diagnosis often struggled more with their social functioning post-treatment. These factors may be used as clinical indicators to identify patients earlier in the care trajectory who may struggle more with social re-integration post-treatment. Additionally, study findings suggest that patients



who travel to receive treatment are more likely to experience social isolation during treatment. Opportunities to foster their continued engagement with their support system at home and to foster new connections with fellow AYAs at the hospital should be prioritized. Too often the social functioning of AYAs goes unaddressed during cancer treatment. There are multiple systems barriers in identifying and addressing social needs throughout treatment, such as time constraints during medical visits, lack of communication between services, and the issue of “ownership” of addressing social needs. All members of the interdisciplinary healthcare team should focus on building trust and rapport with patients and their caregivers early in the care trajectory in order to foster dialogue about social interests, needs, and preferences and to form the foundation for an ongoing relationship to be able to offer age-appropriate support resources in a timely manner as psychosocial and medical needs change throughout the care trajectory.

Opportunities for patients to connect with other young adult cancer patients should be promoted throughout treatment in both pediatric and adult cancer care settings. This will likely involve a combination of web-based, hospital based, and community support resources depending upon patient preferences and AYA oncology resource availability where a patient receives treatment. From the very first clinical encounter at the time of diagnosis, participants describe assessing provider engagement and respect, such as through eye contact (with them versus their parent). Participants consistently emphasize the use of humor and the exchange of social interests when engaging with their oncology healthcare providers. Pediatric and adult oncology providers should receive specialized training about optimal strategies for engaging with AYAs throughout the care trajectory. Study participants describe seeking clear information from their healthcare team about their cancer diagnosis and treatment and supportive resources to help them anticipate and manage medical and psychosocial challenges during and after treatment.

Social stressors and potential barriers to participation in support resources should be discussed openly with patients and caregivers, especially prior to transitions in care. If this does not occur then the appropriate support resources may not be able to be identified and offered. Participants often shared systems barriers, such as limited young adult cancer support resources in certain geographic areas and lack of awareness about AYA cancer support resources, and personal barriers, such as social anxiety and social stigma, when discussing if they had accessed support resources. Among participants who did not access support resources, they usually perceived that they did not need it and/or that they would not have benefited from it. Age appropriate desires to be treated the same by their peers and to maintain their sense of identity independent of their cancer diagnosis seem to strongly reduce interest in accessing cancer support resources. Additionally, AYAs may be less likely to ask for support because they don't want to worry or burden their loved ones. Other participants describe feeling too overwhelmed and exhausted during treatment to locate and access support resources. The timing of when support resources are offered appears to be critical, such that if a resource is introduced too soon, too late, or during a medically stressful time in the care trajectory, it may increase the likelihood that it will not be well received and may be perceived as an additional burden. Resources should be accessible, flexible, and age-appropriate.

### **Research Implications**

Study findings highlight the need for specialized screening and assessment tools to identify patients early in the care trajectory who may be more likely to struggle with social reintegration post-treatment. The complex multi-layered stressors experienced by young adult cancer patients are often hard to capture in a questionnaire. The social functioning screening tools that currently exist are not specific to AYA cancer patients. Participant

feedback regarding the PROMIS measures of social functioning administered in this study suggest that generalized wording such as “I am satisfied with my ability to do things for fun outside my home” may not capture more nuanced social challenges such as worries about being perceived differently by their friends or uncertainty about discussing their cancer diagnosis that may inhibit participation in recreational activities with peers. Some study participants appeared distressed when completing the social isolation questionnaire, in which all questionnaire items were worded in the context of being social isolated, such as “I feel left out”, “I feel that people barely know me”, and “I feel detached from other people”. When screening for social isolation, items should be incorporated that are worded in the context of social connectedness, such as “Some relationships have grown stronger since my cancer diagnosis”.

Inclusion of certain sociodemographic questions on social functioning questionnaires, such as age at the time of cancer diagnosis, type(s) of treatment received (e.g. chemotherapy/surgery/radiation), and whether or not patients had to relocate to receive treatment is also recommended. Further research is needed in partnership with AYAs to develop social functioning screening tools that will more accurately identify patients who are struggling with social functioning during treatment and who may also be more likely to struggle with social re-integration post-treatment.

There is often a mismatch between how participants imagined things would be after completing treatment and the reality of the challenges they continue to face in their daily lives after treatment. Perceived social support from family/peers and the healthcare team, self-efficacy for managing social interactions and treatment effects, mental health needs, and knowledge of treatment effects prior to the completion of treatment should be studied as potential moderators of social functioning post-treatment. In future research, these factors should be studied within and across sub-samples of the AYA cancer population to

help inform more individualized survivorship care. AYAs themselves should be involved in the research process every step of the way. Consistent with findings from Vollmer Dahlke and colleagues (2017), there is an increased desire among AYAs to engage in self and community advocacy. This collaborative engagement will help foster innovative ideas and solutions to ongoing areas of concern, such as adherence with follow-up, making healthy lifestyle choices, and social reintegration.

### **Policy Implications**

There is a robust and active network of patient advocacy groups, non-profits, medical centers, government agencies, clinicians, and researchers working together to eliminate barriers to care and treatment for AYAs, yet many challenges and barriers still exist in the field. There needs to be increased awareness about the social needs of AYAs, more specialized training for providers working with AYAs, and more infrastructure to support the development and implementation of AYA oncology units. Policies should be developed that enable AYAs to receive age-appropriate care that fully meets their developmental, psychosocial, and medical needs throughout the care trajectory.

Critical Mass: The Young Adult Cancer Alliance is the full-time federal advocacy arm of the AYA cancer community in the United States (Critical Mass, 2018). Ongoing legislative advocacy efforts include proposals for insurance companies to provide coverage for AYA fertility preservation, for the HPV vaccine to be added to state immunization requirements, for the protection of federal funding for AYA cancer research, and to allow deferment of student loans during cancer treatment (Critical Mass, 2018).

The financial burden of cancer is uniquely challenging for young adults who lack not only the financial security and life experience of older adults but also the parental support that may benefit youth (Landwehr, Watson, Macpherson, Novak, & Johnson, 2016). Young adults in the United States ages 26 to 34 are more likely to be uninsured

than any other age group (Barnett & Berchick, 2017). Lack of insurance is consistently associated with greater risk of mortality for AYAs of all ages and with nearly all types of cancer (DeRouen, Parsons, Kent, Pollock, & Keegan, 2017) and is strongly associated with the degree of cancer-related financial problems (Fenn et al., 2014). The strongest independent predictor of poor quality of life among cancer survivors is increased financial burden as a result of cancer care costs (Fenn et al., 2014).

Legislation has been proposed to allow deferment of student loans during cancer treatment. The Deferment for Active Cancer Treatment Act of 2017 (H.R. 2976) has been proposed to amend the Higher Education Act of 1965 to allow deferment of certain federal student loans during cancer treatment and in the 6 months post-treatment (National Cancer Institute, 2017). This would help protect young adult patients from experiencing loan interest accrual during cancer treatment. This bill would help prevent unnecessary additional financial burden on young adult cancer survivors already trying to manage the social, psychological, physical, and financial burden of cancer treatment.

Legislative processes often take many years and these are time sensitive issues. There should be direct pathways for AYAs to inform policymakers about the urgency of these issues. There should be policies and guidelines developed to ensure that the social functioning of AYAs is addressed in tandem with medical needs throughout the care trajectory.

## **Conclusions**

This mixed methods study explored the social functioning of young adult cancer survivors ( $N=13$ ; ages 17-25 at the time of cancer diagnosis) during the transition from active treatment to survivorship care. Study findings highlight the complexities of the psychosocial, developmental, and medical needs of young adult cancer survivors. Losses experienced during treatment and changes in social identity cause more uncertainty about

social re-integration post-treatment. Losses involving activities, hobbies, and career development that were integral to the person's identity, such as losing the physical ability to play sports or maintain employment, were described by study participants in the context of how their has life changed since being diagnosed with cancer *and* compared with how their friends lives have continued on. As one participant describes the personal and social aspect of the loss, saying how *"So all of my health troubles have really had a huge impact on myself as an athlete, mainly the stroke, I was still able to practice, I wasn't able to play with my high school team while going through therapy because it was too demanding..."* (P03, age 21, M, Acute lymphoblastic leukemia). Another participant describes having to put his career on hold right as he was about to launch his career, saying *"...the timing of it was, you know, not ideal because I'd just finished college I was starting my career and then you know everything has to be put on hold because you know first and foremost I need to be healthy if I want a career..."* (P09, Age 25, M, Testicular Cancer). Another participant describes feelings of loss seeing her peers' theatre activities on social media, *"...it's been kind of difficult, being chained to an IV pole, not really 100% of the time but kind of, cause the, like on Instagram I would see all of this like, the people that I went to school with doing all these really cool productions and like, well, ok..."* (P01, age 19, F, Hodgkin's lymphoma).

Study participants often experienced reduced self-efficacy for managing social interactions during the transition from active treatment to survivorship care. Participants returning to college after treatment described this reduced self-efficacy in terms of worries about feeling overwhelmed and overloaded in the college environment. One participant shares how, *"And I'm like definitely very nervous for kind of going back and just being like overloaded, or like overwhelmed with kind of like everyone all of a sudden being like back in my life, you know...and just like asking a lot of questions..."* (P13, age 22, F, Non-

Hodgkin's lymphoma). Another participant anticipating her return to college says, "*it's such a weird transition to like be in college, and then not be in college and have to go back...*" (P08, age 19, F, Hodgkin's lymphoma). Even among participants who were able to maintain employment during treatment, this reduced self-efficacy was described in the context of concerns about being perceived differently by their employer. One participant shares in her follow-up interview how she obtained a new job after treatment ended because of concerns of how she would be perceived by her employer where she had worked during treatment, "*...I didn't necessarily want to go back to the same work that I had worked for, just because I didn't want the sympathetic eye or that, you know, notion of always, that question of how my performance so I wanted to shift gears in that...*" (P06, age 27, F, Ewing sarcoma). Participants seeking employment after treatment described concerns about potential employers noticing their cancer diagnosis by their physical appearance (e.g. their hair not grown back in yet) during the interview process. Another participant shared his concerns about his peers perceiving him differently, describing "*you know the way people like looked at me and saw me was kind of my biggest challenge, was you know I wanted to be seen as [patient name] beforehand, just regular [patient name], but now, I you know, I was going through treatments, I was you know, [patient name], [patient name] has cancer, couldn't separate those two...*" (P09, Age 25, M, Testicular Cancer).

There was usually a mismatch between how participants imagined things would be after completing treatment and the reality of the challenges they continued to face in their daily lives after treatment. One participant shares how much she anticipated returning to college after completing treatment and the loss she experienced at the last moment when she was unable to go back to school due to getting CMV virus, saying "*Everything was in order, everything was great, I was almost all, I was getting ready to be packed up and then I like, cause I wasn't able to eat, I wasn't able to drink, I lost a lot of the body weight that*

*I had gained back...it was just like not good, I was feeling sick and I really wanted to go back and since all of my friends are back and um at school I'm one of those students that feels kind of just left out..."* (P01, age 19, F, Hodgkin's lymphoma). Another participant shares how, *"I think like, even just thinking that like oh like the day I finish radiation is like the day I'm like completely done with treatment and I'll feel 100% better, it's just not realistic..."* (P08, age 19, F, Hodgkin's lymphoma).

Young adult survivors who experienced more severe physical treatment effects, who had unaddressed mental health needs, and who were younger at the time of cancer diagnosis experienced more impairment in social functioning post-treatment. Participants who experienced more severe physical treatment effects often described ongoing challenges with their daily functioning post-treatment and changes in their social identity. One participant who has suffered from severe complications post-bone marrow transplant describes how his identity has changed using a powerful metaphor of who he was before dying, saying *"Whoever you were when you got diagnosed, they died. Because your whole, your whole mindset, your whole understanding of yourself and your body is going to be completely different..."* (P12, age 23, M, Acute myeloid leukemia). In contrast, another young adult male participant with leukemia who did not experience severe physical affects after his bone marrow transplant describes not letting cancer hold him back and seeking to return to the same person who he was five years ago, saying *"I wanna get to the same person I was 5 years ago, I wanna be that same person again you know, and not say, not blame cancer about what I can't accomplish or anything like that..."* (P04, age 24, M, Acute lymphoblastic leukemia). A study participant struggling with limited mobility in walking post-treatment describes how much her illness impacts her conversations with her peers saying, *"Umm I don't know I feel like when a lot of people talk to me they bring up questions about my health or they're curious because they don't really, they haven't been*



*there through like everything...Um questions get really annoying...*” (P10, age 22, F, Acute lymphoblastic leukemia). In contrast to participants who describe no longer having outward physical signs of their cancer diagnosis post-treatment, saying that *“I'm completely healthy, and you know there's nothing physically about me that screams you know he's been through cancer...but going through the first initial shock of it, that was the most frustrating part, when people looked at me I didn't want them to see a frail, illness ridden human being”* (P09, Age 25, M, Testicular Cancer).

In regards to unaddressed mental health needs during treatment, one participant describes her perception of the contrast between her medical needs being treated and her psychological needs being unaddressed, saying *“I don't know it's just like a little bit strange to me cause like they go to all of these lengths to make sure that you're like physically ok, when it's like the mental aspect can be like just as debilitating so, yeah I feel like there's a big lack of it there, like it's almost like let's like not talk about it and you know like, let's not ask about it cause then we'll have to like do something...”* (P08, age 19, F, Hodgkin’s lymphoma). Another participant describes being asked mental health screening questions, and shares his perspective about being asked about if he feels supported, saying *“I don't really know how to answer that question...do I feel like I'm out on an island? No. Do I feel like I'm standing atop the right hand of God? No. It's up and down, sometimes I feel like we're all in this together and other times it's like I'm the only one who wants to see me get better in a healthy way... the doctors are going to be keep me healthy, but not necessarily in the best quality of life. They're going to sacrifice quality of life every single time...”* (P12, age 23, M, Acute myeloid leukemia). In contrast, a study participant who participated in skills-based therapeutic support programming throughout treatment describes how it has helped her, saying *“...it's like a skills-based kind of workshop, which I really like, and we kind of talk about like strategies for like coping with things like anxiety*

*and kind of like talking about the different faith problems we face and kind of really, instead of like support groups I feel like you're kind of just, like putting it all out there, it's like here it's really like strategies of how to deal with it..."* (P13, age 22, F, Non-Hodgkin's lymphoma).

In regards to age at the time of cancer diagnosis, the study participant who was first diagnosed with cancer as an adolescent describes ongoing challenges with participating in social activities with her peers due to her parents concerns, "...when I can I try to do things on my own which is kind of hard to be independent when my parents still have a really hard time of like letting go and like letting me go out by myself or like I always have to let them know where I am, which is, I just find it like a little annoying..." (P10, age 22, F, Acute lymphoblastic leukemia). Another participant diagnosed at age 18 describes challenges with trying to make new friends after treatment, saying "I haven't met anyone that has quite has the same sort of overlapping interests, and more importantly, things have narrowed down a bit uh not sure when to get started and sort of start talking, especially to people my own age again..." (P11, age 19, M, Rhabdomyosarcoma). Additionally, another participant diagnosed during her first semester of college describes how she doesn't have the energy to make new friends and she wasn't solidified with her friend group in college before her diagnosis, saying "I didn't have like super amazing friends, just in that short time, like it was like, you know I was still forming friendships and finding like my group and everything, kind of like having to leave and then try to come back like after the spring and summer, and then on top of it just feeling like super tired and not able to like, not able to like join clubs..." (P08, age 19, F, Hodgkin's lymphoma). In contrast, a study participant diagnosed at age 25 describes how having a strongly bound social support system and more experiences with coping with life challenges has helped her, saying "...I'm really grateful to have my family that you know just appreciates that I don't take it too hard about things,

*and I just kinda let it go and then move on cause it's not the end of the world...The same things with my friends and my partner, it's just, you know it's a good support group to have to fall back on and just like cry your eyes out one day and then being like alright, moving on, let's go, what do I have to do next?"* (P06, age 27, F, Ewing sarcoma).

Study findings highlight the need for specialized screening and assessment tools to identify patients early in the care trajectory who may be more likely to struggle with social reintegration post-treatment and to provide referrals to age appropriate resources as needed. The timing of when support resources are offered appears to be critical, such that if a peer survivor is introduced too soon, too late, or during a medically stressful time in the care trajectory, it may increase the likelihood that it will not be well received and may be perceived as an additional burden. One participant describes being introduced to a peer survivor in the beginning of her cancer treatment during a very medically stressful, saying *"when I first got diagnosed I was actually hospitalized, my oncologist brought some random girl who was just finished, same disease, same diagnosis, same stage and everything, who just finished up her treatment in to see me, and she started talking to me, and I'm just like, it was just like, crickets. So I think her, her experience was way different than mine so at the time I was experiencing a lot of like, cause the first two cycles and I remember I, I was like, my face, dragged on ASPHALT. My ass was given to me, and this girl I was asking her experience, and like do you have a PIC port? ...and she was like WHAT? What are these things? And she was the same age as I was, and I was like thank you, goodbye! I deal with this by myself, by myself. I don't want to talk to you, or anyone like you..."* (P01, age 19, F, Hodgkin's lymphoma). Another participant describes being connected with other young adult cancer patients during treatment and becoming more stressed and anxious by hearing about their worsening health, saying, *"when I was going through it uh I met I met people you know they introduced people to me and then umm like*

*from one day to another people would like, like, pass, like you know, like they would go through stuff I never went through, you know some of them passed away...every time I try to like talk to them or anything like I would hear ugh they're sick or they're at the hospital or something is very wrong you know... it did sound scary, you know and it would bring me down just hearing about it, you know, someone's at the hospital cause of this, so then I started worrying myself about what I'm doing wrong, or what I'm doing that they're doing, the things that would worry me, so that would bring my mood, I wouldn't be in my bubble you know..."* (P04, age 24, M, Acute lymphoblastic leukemia). However, when peer supports were introduced at a less medically stressful time in the care trajectory, such as upon completion of active treatment, participants described positive experiences with meeting peer survivors, such as *"I went on a kayaking trip and I invited my brother along and, another thing is umm I thought I had one of the rarest cancers, and three girls in the same group, all of us have the same cancer, and it was just kind of like eye opening to see that you know you think you're alone but you're not cause other people just you know our age so that was really nice, it was a really fun weekend to do with them..."* (P06, Age 27, F, Ewing sarcoma). Another participant describes how much it helped him and his Mom and his girlfriend finally getting to meet other young adult males with testicular cancer at a conference he was able to attend after treatment, saying *"I didn't, you know, meet anybody until I went to this conference that actually had testicular cancer so it was, it was really great to hear their stories and to hear how they went through and how they've persevered so that was, that was a huge experience for me, and for my girlfriend and Mom who also came with me..."* (P09, Age 25, M, Testicular Cancer). Opportunities for AYAs to stay involved socially and professionally should be fostered throughout treatment and beyond.

## **APPENDICES**

### **Appendix A: Code Frequency & Co-Occurrences**

<b>Code</b>	<b>Frequency of Occurrences</b>	<b>Most Frequently Co-Occurs With</b>
Interactions with Support System	257	Coping Strategies & Treatment Effects
Interactions with Healthcare Team	193	Advocating/Staying Informed & Treatment Effects
Treatment Effects	187	Post-Treatment Experiences & Interactions with the Healthcare Team
Coping Strategies	177	Interactions with Support System & Treatment Effects
Support Resources	126	Seeking/Meeting AYAs & Interactions with the Healthcare Team
Post-Treatment Experiences	103	Treatment Effects & Support Resources

### **Appendix B: Member Checking Feedback**

Four participants responded with their feedback about the study findings. One participant (P08, age 19, F, Hodgkin’s lymphoma) responded, “*I think that your findings*

*are really well put, I wouldn't add anything!"* Another participant (P06, age 27, F, Ewing sarcoma) responded, *"I'm sorry I've been on back to back trips for work and personal reasons and letting my inbox pile up. But this looks great!! Thank you for allowing me to be a part of this study and your research. It was so nice chatting with view and strangely this put things in perspective of what was and what is and what will be."* Another participant (P02, Age 22, F, Wilms Tumor) added notes about interactions with the healthcare team, treatment effects, coping strategies, and post-treatment. She noted that in regards to making their voice heard in treatment decision-making processes that *"also realizing that you don't know enough about these decisions and are struggling for life. Afterwards we realize how little we knew"*. In regards to managing physical treatment effects, she adds *"also the memory loss and lack of focus. It's difficult to maintain a conversation when you can't remember what they were saying no matter how hard you try to remember."* In regards to coping strategies, she notes, *"also learning to accept your body for how it is, for how it is reacting."* In regards to post-treatment managing expectations, she adds, *"also noting the difference between cancer you and real you. There are some side effects that go unnoticed as you're struggling through treatment, but when you watch your body change back to what it was before, you realize how bad it was."*

Another participant (P09, Age 25, M, Testicular Cancer) also provided his feedback:

*"I have read through your findings, and I couldn't agree more with all of your conclusions! As for how we can utilize these findings to help other young adult cancer patients, I think it's more of a question of how we can get this information into the hands of young adult cancer patients. Personally, if I would've been able to read these findings as I was going through treatment and into survivorship, I*

*believe that I would've been more prepared to deal with the social issues that resulted from my diagnoses.”*

### **Appendix C: Sociodemographic Questionnaire**

1. What is your current age? \_\_\_\_\_ years old



2. What was your age at the time of your cancer diagnosis? \_\_\_\_\_ years old

3. What is your gender?

Male

Female

Non-binary/third gender

Prefer to self-describe: \_\_\_\_\_

Prefer not to say

4. What is your race/ethnicity/origin? (please check all that apply)

Non-Hispanic white

Non-Hispanic black

Hispanic or Latino

Native American or American Indian

Asian/Pacific Islander

Other race/ethnicity/origin (please specify): \_\_\_\_\_

5. Please circle the highest year of school you have completed:

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17+
(primary)						(middle/high school)						(college/university)				(graduate school)

**Appendix C: Sociodemographic Questionnaire (cont.)**

6. What is your cancer diagnosis? \_\_\_\_\_

7. What type(s) of cancer treatment have you received? (please check all that apply)

Chemotherapy

Surgery

Radiation

8. What was your health insurance status at the time of your cancer diagnosis?

Uninsured

Insured

## **Appendix D: Interview Guide**

### **Time 1**

Thank you so much for sharing your time to participate in this study.

- 1) Can you tell me a little about yourself? I'd love to learn more about your talents and interests.
- 2) Who has helped support you throughout cancer treatment?
- 3) Can you tell me about any support resources you may have accessed during your cancer treatment?
- 4) What would you recommend as helpful to fellow young adult cancer patients? ...And things that were frustrating or challenging about accessing support resources?
- 5) Have there been times that you have felt alone or isolated during treatment? Can you tell me a little more about this?
- 6) How do you feel about navigating social situations as you transition into survivorship care?
- 7) How can your health care team continue to help support you?
- 8) Anything that I didn't ask you about that you'd like to share with us?

**Time 2**

- 1) It's so great to talk with you again...how have you been doing over the past few months?
- 2) Who has helped support you in the transition to survivorship care?
- 3) Can you tell me about any support resources you may have accessed during the transition to survivorship care?
- 4) Have there been things you'd recommend as helpful to fellow young adult cancer patients? ...And things that were frustrating or challenging about accessing support resources?
- 5) Have there been times that you have felt alone or isolated over the past couple months since you finished treatment? Can you tell me a little more about this?
- 6) Can you tell me about if your feelings have changed since finishing treatment about navigating social situations?
- 7) How can your health care team continue to help support you?
- 8) Anything that I didn't ask you about that you'd like to share with us?

## **Appendix E: Member Checking Form**

### Interactions with Support System

#### ***Being There***

-Usually identified one person who was there with them throughout treatment and provided both emotional support and assistance with navigating the medical system

#### ***Staying Strong***

-Desire to feel supported by friends and family but not sharing as much worries or sadness with them because of not wanting to worry or upset them

#### ***Treat Me the Same***

-Desire to be treated by peers in the same way as before they had cancer

### Interactions with the Healthcare Team

#### ***Connection & Relationship Building***

-Connecting with healthcare team on a deeper, more personal level – engaging with humor, sharing social interests, building trust

#### ***Seeking Knowledge & Engaging in Advocacy***

-Seeking information about their cancer diagnosis and treatment, asking questions to their healthcare team, making their voice heard in treatment decision-making processes

### Treatment Effects

#### ***Uncertainty, Loss, & Changes in Identity***

-Fear of cancer recurrence, changes in personal identity and body image, uncertainty about being socially with peers again

#### ***Ups & Downs of Physical Symptoms***

-Managing physical treatment effects -- fatigue, nausea, feeling crappy *and* having to be friendly and social with visitors

### Coping Strategies

#### ***Keep Busy***

-Try to stay active and involved in activities as much as possible during treatment, stay distracted with movies, music, podcasts, & books

#### ***Keep a Positive Vibe***

-Try to maintain a positive attitude, mind-body connection with keeping positive vibes and managing physical treatment effects

### Support Resources

#### **Support needs change over time**

-Resource needs and preferences will vary throughout treatment and after treatment depending upon medical needs and personal circumstances

### Post-Treatment Experiences

#### **Trying New Things to Cope with Losses**

-Looking ahead to the future, taking trips, starting/returning to work or school, trying new activities

#### **Managing Expectations with Realities**

-Sometimes things feel different and harder after treatment than it seemed they would, some uncertainty about hanging out with peers again and talking about cancer diagnosis

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