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Occupied with Cancer: Trajectories of Employment/Education and Psychological Distress among Socioculturally Diverse Adolescent and Young Adult Cancer Patients

A dissertation submitted in partial satisfaction of the
requirements for the degree Doctor of Philosophy
in Social Welfare

by

Christabel Kar-Yin Cheung

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ABSTRACT OF THE DISSERTATION

Occupied with Cancer: Trajectories of Employment/Education and Psychological Distress among Socioculturally Diverse Adolescent and Young Adult Cancer Patients

by

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Doctor of Philosophy in Social Welfare
University of California, Los Angeles, 2017
Professor Robert Schilling, Chair

The primary question that this dissertation research investigates is how trajectories of employment/education and psychological distress are characterized across two years following a cancer diagnosis among socioculturally diverse adolescent and young adult (AYA) patients, and whether and how change in occupational status is associated with psychological distress over time. Within this overarching question, the researcher examines the following specific aims: (1) To identify longitudinal trajectories of psychological distress (Bonanno, 2004) among AYA cancer patients across two years following initial cancer diagnosis, and depict the association between psychological distress and treatment status, health status, and sociocultural factors; (2) To examine the relationship between theoretical trajectories of occupational status and psychological distress across two years after initial cancer diagnosis among AYA cancer patients, including examination of treatment status, health status related to readiness to work, and sociocultural factors.

The study used the HopeLab longitudinal dataset (Zebrack et al., 2013), a prospective longitudinal study of 215 AYA cancer patients ages 14-39 years across two-years following a cancer diagnosis, from three institutions: University of Southern California/Children's Hospital Los Angeles, University of Texas Health Science Center at San Antonio, and Oregon Health and Science University. The methodology included descriptive analyses to define and characterize trajectories of occupational status and trajectories of psychological distress, bivariate analyses to test hypothesized associations with psychological distress trajectory, and linear mixed modeling for multivariate analyses of change in psychological distress over time.

The overall trend in psychological distress among AYA cancer patients across the two-year observation period formed a U-shaped curve that bottomed out at 6-month follow-up, then climbed to its highest level at 24-month follow-up. On average, psychological distress at 24-months following cancer diagnosis was worse than at baseline. Furthermore, theoretical trajectories of occupational status among AYA cancer patients are identified and named. Multivariate results indicated that being male and being Non-White were each significantly associated with increased psychological distress among AYA participants, while being on treatment and having fatigue were associated with decreased psychological distress. Consistent with the building body of knowledge on mental health among AYA cancer patients, this dissertation research contributes longitudinal findings that expand the limited available evidence on occupational status change and psychological distress among socioculturally diverse AYA cancer patients. Future research should investigate ways to support the mental health of cancer patients who must maintain education/employment roles following a cancer diagnosis, with more specificity related to various occupational and sociocultural contexts.

Keywords: Cancer, young adult, survivorship, psychological distress, return to work, reintegration to school, longitudinal study

The dissertation of Christabel Kar-Yin Cheung is approved.

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2017

To Malcolm, the best cancer support dog in all of existence,

and Dr. Susana Ming Lowe.

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Acknowledgments

The dissertation research presented here used data from the Hopelab longitudinal dataset, which was developed by principal investigator Bradley J. Zebrack, PhD, MSW, MPH, Professor at the University of Michigan School of Social Work, with funding support from the HopeLab Foundation.

Adolescent and young adult cancer patients are outliving cancer well enough to return to work and school. When I began doctoral studies at UCLA, I was over one year out from intensive cancer treatments for my second diagnosis of Hodgkin's lymphoma, and just beginning to call myself a two-time cancer survivor. Like many other young patients, the symptoms, side-, late-, and long-term effects of cancer treatments were communicated to me, but guidance on when and how to return to work/school was vague at best. An understanding of participation in work/school that optimizes well-being can help young patients to manage and prevent problems that may impact work performance in the crucial early stages of their professional careers.

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CHAPTER 1

INTRODUCTION

Purpose of Study

When adolescents and young adults are diagnosed with cancer, life-threatening illness jeopardizes not only their lives; it also disrupts participation in work and school roles with implications for future employability and financial prospects that affect the remainder of their lives (Arnett 2000; Chisholm & Hurrelmann, 1995; Craig, 2006). The primary question that this research investigates is how trajectories of employment/education and psychological distress are characterized across two years following a cancer diagnosis among socioculturally diverse adolescent and young adult (AYA) patients, and whether and how change in occupational status is associated with psychological distress over time. To answer this overarching question, the researcher pursued two specific aims. In aim one, the researcher drew upon Bonanno's (2004) Stress-Coping Model to identify longitudinal trajectories of psychological distress among AYA cancer patients across two years following initial cancer diagnosis, and depict the association between psychological distress and treatment status, health status, and sociocultural factors. In aim two, the researcher examined the relationship between theoretical trajectories of occupational status and psychological distress across two years after initial cancer diagnosis among AYA cancer patients, including examination of treatment status, health status related to readiness to work, and sociocultural factors.

Background

One of the greatest achievements in cancer treatment and research in the United States (U.S.) is the dramatic increase in the number of cancer survivors, many of whom might not have lived this long 30 years ago (Aziz, 2002). Due in large part to successes in cancer research, overall cancer survival rates in the U.S. have improved, with the total number of cancer survivors in 2014 estimated at 15.5 million and growing (American Cancer Society [ACS], 2016b). Fifteen percent of these cancer survivors have survived 20 years or more (de Moor et al, 2013). When disaggregated, however, cancer survival rates for adolescents and young adults (AYA), diagnosed between ages 15-39 years lag behind those of pediatric and older adult cancer patients, and have remained unchanged for the past 30 years (Bleyer, 2011).

Treatment innovations are credited for increasing adolescent patients' (ages 15-19) five-year overall survival rates to exceed 80% for most cancers (Sender & Zabokrtsky, 2015). Nonetheless, cancer remains the leading cause of disease-related, non-accidental death among AYAs in the U.S. (Center for Disease Control and Prevention [CDC] & National Cancer Institute [NCI], 2015). Despite cancer being more commonly observed in older populations, AYAs comprise a sizeable patient care population. In 2016, there will be an estimated 1.7 million new diagnoses of *invasive cancer,* and of these, over 70,000 will be AYA ages 15-39 years (ACS, 2016a). An indication of more serious disease, invasive cancer is defined as spreading beyond the layer of tissue in which it developed and growing into surrounding, healthy tissues (NCI, 2017). Seventy thousand AYAs may seem like a small proportion of the total 1.7 million new cancer diagnoses, but consider that this number is six times that of pediatric cancer, and 40% higher than the total number of new HIV cases diagnosed each year (CDC, 2015). Distinct from adolescents and young adults who were diagnosed with cancer as younger children, patients diagnosed with cancer as adolescents and young adults are simultaneously confronted with the challenges of a transitional life stage and the biopsychosocial issues of survival from cancer, including increased health risks, late- and long-term side effects, loss of fertility, threats of mortality, and disruption to employment and education (Bleyer, 2011; Bleyer & Barr, 2007; Zebrack & Isaacson, 2012; Zebrack et al., 2013).

Over the last decade of building research and acknowledgement of the unique biomedical and psychosocial needs of the AYA patient care population, the oncology community has sharpened its focus on cancer diagnosed during adolescence and young adulthood. Notably in 2006, the National Cancer Institute partnered with the Livestrong^{TM} Young Adult Alliance to convene a Progress Review Group that produced recommendations for a national agenda to advance adolescent and young adult oncology (Albritton et al., 2006). The resulting summary report called for greater attention to core topics in the AYA cancer problem – namely, biology, prevention/cancer control/epidemiology/risk, insurance, clinical care models, psychosocial/behavioral factors, and long-term effects (Albritton et al., 2006). In 2013, the National Cancer Policy Forum of the Institute of Medicine (now known as the National Academy of Medicine) convened a public workshop entitled, “Identifying and Addressing the Needs of Adolescents and Young Adults with Cancer,” which highlighted psychosocial issues that disproportionately affect AYAs due to their developmental life stages (Nass et al., 2015). Today, the American Society for Clinical Oncology (ASCO) asserts that cancer prognosis for young adults with cancer is worse than it was 25 years ago, and responds by offering “Focus Under Forty,” a continuing education course for clinicians focused on the unique biology and care issues associated with AYA cancer (American Society for Clinical Oncology, 2016).

Theories of Adolescent and Young Adult Development

Against a singular message of “distinctness.” Chad Hammond’s (2016) theorization of AYA cancer patients’ development is the principle theory of AYA development in the present research, as it proposes an alternative to the commonly stated contention that AYAs are explicated by one shared and concise characterization as a singular, distinct cohort, tasked with achieving the same ordered set of developmental tasks. Hammond (2016) theorizes a much more sophisticated depiction of the lives of AYA cancer patients by presenting four interrelated sociodemographic contexts. First, the precarious labor conditions affecting AYAs' financial and work lives are important to consider, as employment among young people tends to be the least secure in terms of income and benefits. Owing to the sociopolitical context of heightened financial instability and un(der)employment, AYAs are nicknamed the "precariat," (Standing, 2014). Financial barriers to cancer care among AYAs are often raised; however, their financial precarity, access to employment, work-related identities, basic rights, and social security are often overlooked (Hammond, 2016). Non-wage benefits that have been shown to help employed cancer patients, but are typically unavailable to low-wage workers, include employer-sponsored health insurance (Swanberg et al., 2017), paid leave (Peipens et al., 2012), and flexible work hours (Pryce et al., 2007).

Second, AYAs' developmental priorities are socially evolving. Changing timelines and priorities for developmental tasks mean that fewer young people are achieving traditional milestones of adulthood, such as postsecondary education, independent living, career, marriage, and children (Hammond, 2016). Such departures from normative pathways towards adulthood are often assessed as failures within AYA oncology, when a broader range of acceptable developmental trajectories should be considered. For example, being unmarried and/or lacking career direction well into one's 30s are not conditions intrinsically tied to developmental delay.

Third, the plurality of sexual orientation and gender identity among AYAs calls for the acceptance of their socially evolving and deeply personal nature (Hammond, 2016). The intersection of sexual orientation and/or gender identity with AYA cancer is commonly seen when cancer treatments threaten AYA patients' fertility. For example, fertility preservation is often a major priority in AYA oncology, with institutionalized pressures to preserve fertility that are biased in favor of sexually monogamous heterosexual men, such as testicular cancer patients (Carpentier & Fortenberry, 2010). This neglects the preferences of AYAs who may not wish to pursue oncofertility interventions based on a host of possible sociocultural influences.

Fourth, and finally, the expanding cultural diversity of the AYA population points to a trend of increasing racial/ethnic disparities and a multiplicity of culturally defined AYA developmental trajectories, which the AYA oncology community has been criticized for omitting from AYA care, despite widespread efforts to promote "cultural competence" in health care (Hammond, 2016). The complexity of disparities associated with social and cultural differences among AYA cancer patients that are relevant to the contexts in which they receive cancer care and live post-treatment, still needs to be identified, understood, and intervened upon.

Emerging adulthood. Introduced as a stage between Erikson's description of adolescence and young adulthood, Arnett's (2000) conceptualization of *emerging adulthood* distinguishes the period of life from the late teens through the twenties as one in which individuals are in some ways an adolescent and in some ways a young adult, but not exclusive to either developmental stage. Defined as ages 18-29, emerging adulthood is a developmental period of profound change and importance, characterized by change and exploration (Arnett, 2014). Although Arnett puts emphasis on ages 18-29 as the most *volitional* years of life, he asserts that these boundaries may differ between individuals due to demographic shifts and diverse sociocultural influences.

Contrary to prior generations, emerging adults' subjective sense of having attained adulthood is tied to individualistic character attributes, rather than the achievement of life transitions such as career advancement, marriage, and parenthood (Arnett, 2000). Furthermore, across several studies, emerging adults most commonly named accepting responsibility for oneself, making independent decisions, and becoming financially independent as top indicators of being an adult (Arnett 1997, 1998; Greene et al., 1992, Scheer et al., 1994). For AYA cancer patients, critical building blocks of employment and education that typically pave the way towards financial independence for their same-age peers are disrupted by life-threatening illness (Arnett 2000; Chisholm & Hurrelmann, 1995; Craig, 2006).

AYA cancer survivors must simultaneously resolve the typical conflicts of normal psychosocial development with the anomalous trauma and persistent challenges of life-threatening illness. In their review of the literature on the provision of support groups for AYA patients with cancer, Treadgold and Kuperberg (2010) stress the striking differences in lived experiences within the AYA age range of 15-39 years, as it includes a diverse mix of human developmental life stages. Indeed, the psychosocial issues of a 15-year-old re-entering high school and those of a 39-year-old working parent starkly differ. Although the demarcation of developmental life stages is not set in stone, well-established theoretical frameworks provide helpful guidelines for understanding the rites of passage in AYA psychosocial development and make the case that the burden of cancer diagnosed during AYA years makes it harder for individuals to achieve essential developmental milestones such as participation in work/school roles.

Intrapersonal growth and turmoil. According to Erikson's (1959) stages of human psychosocial development, adolescence is loosely defined as ages 12 to 18, but extends into later years in more industrialized societies. The central developmental task of this life stage is to resolve the personal conflict between identity and identity diffusion, in which the adolescent moves through a tumultuous process of identity formation; the positive outcome of which is emergence with an ability to stay true to oneself as opposed to a weak sense of self. This process is tumultuous as it is characterized by the onset of radical physical and psychological changes such as puberty and genital maturation, first-time intimacy with the opposite sex, and new autonomy to make seemingly conflicting choices about their lives. It is important for health care providers working with AYAs to recognize that inconsistencies in self-identity are a natural part of AYA development.

Consistent with their developing intrapersonal skills, AYA cancer survivors often lack the maturity and skills to incorporate the experience of cancer into their lives, and have difficulty maintaining personal motivation through long periods of treatment if they are unable to achieve what they perceive to be a reasonable quality of life (Morgan et al., 2010). According to Erickson et al.'s (2013) review of the literature on symptoms and symptom clusters in adolescents receiving cancer treatment, as a reflection of emotional volatility, adolescence is marked by high morbidity and mortality associated with homicide, suicide, depression, risky sexual behavior, alcohol and substance abuse in this age group. In a study on the health status of AYAs diagnosed with cancer between ages 15-29, Tai et al. (2012) characterized AYA survivors as exhibiting unhealthier behaviors than people without a history of cancer, with findings indicating that AYA survivors smoke more and exercise less, have a higher prevalence of chronic medical conditions and obesity, poorer mental health, and have more financial barriers to medical care access.

Interpersonal relationships and barriers. Following the establishment of a reasonable sense of personal identity, Erikson (1959) suggests that the adolescent progresses into young adult psychosocial development with the primary conflict being between personal intimacy and isolation. Young adults (usually defined as ages 19-40) are focused on cultivating the capacity for personal intimacy in the form of interpersonal relationships surrounding friendship, combat, leadership, love and inspiration (Erikson, 1959). A cancer diagnosis can disrupt these developmental changes and affect the achievement of self-esteem and independence (Corey et al., 2008).

AYA cancer patients require careful assessment of their individual psychosocial development and functional capacity to avoid harm, as their personal wishes and expressed preferences may be questionable or changing due to their life stage. Typical power struggles inherent to AYAs' interpersonal relationships with their parents and other authority figures are heightened in the context of life-threatening illness. For example, retaliation against authority, which is a typical and harmless feature of interpersonal development for AYAs (Erikson, 1959), may have much higher stakes involved when such defiance shows up as skipping out of cancer treatments. Underscoring the severity of AYAs who act against medical advice, Butow et al. (2010) explain that non-adherence to cancer treatment protocols can threaten treatment efficacy, and result in increased risk of relapse, adverse effects and poor outcomes.

State of Knowledge

Conflicting definitions of the AYA age range. Although the broad definition of AYA as comprised of ages 15-39 is most commonly used by cancer care providers and researchers, there are widespread inconsistencies in defining the AYA age range in the literature (Aubin, 2011). Geiger and Castellino (2011) detailed this challenge to oncology care and research in their letter to the editor of the *Journal of Clinical Oncology,* calling for explicit definitions and clear rationale for age ranges used in articles published in the journal's issue dedicated to AYAs. Furthermore, in their review of the literature on the provision of support groups for AYA patients with cancer, Treadgold and Kuperberg (2010) stress the important differences in lived experiences within the category of AYA ages 15-39 due to the diverse mix of human developmental life stages within it. However, the NCI's (2006) first-of-its-kind Progress Review Group on Adolescent and Young Adult Oncology defined AYA as an even broader age range of 14-39 years. Consistent with the age range used by the NCI (2006), the current study defined AYA as ages 14-39, and use of any narrower definitions of AYA are explicitly named and explained. By using this broader definition of the age range, a wider scope of AYA issues related to both are revealed and subsequent study can look deeper within sub-categories such as teens/adolescents, 20s, 30s, and other permutations as relevant.

Sociocultural factors defined. An application of Lev Vygotsky's (1980) sociocultural theory, the present research examined the influence of sociocultural factors defined as aspects related to minority social and/or cultural status within the context of a mismatched set of dominant norms and values. In an increasingly diverse multicultural society, the population of AYA cancer patients ages 14-39 is comprised of a heterogeneous mix of age cohorts, developmental stages, personal identities (race, ethnicity, gender, sexual identity), and lifestyles that influence AYAs' knowledge, attitudes, beliefs, and subsequent behavioral responses to cancer – e.g. adherence to therapy, use of alcohol/drugs, social involvement, ability to manage treatment side effects (Hammond, 2016; Warner et al., 2016). Membership in a disparaged racial and/or ethnic minority group presents AYAs, who are still forming their sense of identity, with added challenge (Phinney, 1989; Tajfel, 1978). Furthermore, negative self-appraisal among AYA cancer patients is associated with increased social isolation, truancy from school, and poor academic performance (Evan & Zeltzer, 2006).

AYAs are medically distinct. Medically, the spectrum of malignant diseases in AYAs is distinct from their older adult and pediatric counterparts, with significant differences in terms of host biology, cancer type, and related treatment strategies (Bleyer, 2002; Bleyer et al., 2008; Sender & Zabokrtsky, 2015). AYA cancer patients may be diagnosed with the same cancer type as their younger or older counterparts, but face much worse prognosis due to their age group. For example, acute lymphoblastic leukemia (ALL) boasts a 90% rate of complete remission with first-line chemotherapy for pediatric patients, but success rates for initial treatment begin to decline with increased age among AYA patients, with full remission of disease in only 20-40% of non-pediatric patients (Rowe et al., 2005). Better ALL outcomes among pediatric cancer patients are attributed to better responses to existing treatment strategies, compared to their older counterparts (Katz et al., 2015).

In another example, Anders et al. (2008) found that young age at diagnosis of breast cancer is correlated with worse prognosis and more negative disease features. Specifically, women 35 years of age and younger have worse prognosis, with greater chance of having an endocrine-unresponsive tumor that grows independent from hormones, higher grade disease that is fast-growing, and more extensively proliferating and vessel invading disease (Colleoni et al., 2002). More aggressive or rare disease calls for more aggressive and less known consequences of treatment strategies, and with more years left in the balance, younger survivors have a greater likelihood of experiencing late and long-term effects of cancer treatment.

Within the AYA age span, approximately 90% of invasive cancer diagnoses are seen in the following ten groups, listed by rank order: breast cancer, lymphomas, melanoma, female genital tract tumors, thyroid carcinoma, sarcomas, testicular cancer, colorectal carcinoma, leukemias, and brain tumors (Bleyer, 2008). Disaggregated for AYAs ages 15 to 19 years, the ranked list of most frequent cancers is: lymphomas, leukemias, sarcomas, and brain tumors (Bleyer, 2006). However, for AYAs ages 20 to 29 years, this ordered list of top cancers is: lymphomas, melanoma, thyroid, and testicular (Bleyer, 2006).

AYAs face unique psychosocial issues. Psychosocially, AYA cancer patients face a deeper and broader scope of practical and social problems that are intensified by their life stage. Within health care settings, AYA cancer patients are challenged with disparate access to clinical trials, lack of age-appropriate supportive care services (Sender & Zabokrtsky, 2015), and low participation in follow-up health care (Harlan et al., 2011). In the broader context of their lives, some biopsychosocial issues among AYA cancer patients include disruptions to school or work, increased dependence on parents, financial challenges, loss of reproductive capacity, premature confrontation with mortality, changes in physical appearance, and health-related concerns about the future (Zebrack et al, 2013).

Cancer disrupts employment and education. Congruent with their still-maturing cognitive and interpersonal skills, many AYA cancer patients lack the capacity to cope with the disruption of cancer in their lives (Morgan et al., 2010), and are likely to abandon cancer treatments if they are unable to achieve what they perceive to be a worthy quality of life (Butow, 2010). While timely matriculation through education and keeping up with same-age peers may be of central importance to AYA cancer patients on the younger end of the 14-39 age spectrum, those on the older end are often concerned with realizing progress in work and employment towards securing financial independence and attaining a desired career goal (Nass et al., 2015). By achieving age-appropriate milestones in employment and education, even as they face cancer, AYA patients are able to maintain a sense of normalcy that is essential to their perceptions of self-worth and quality of life (Choquettte et al., 2016; Ganz, 2007; Georgiadi & Kourkoutas, 2010; Kwak et al, 2013; Mehnert, 2011; Morgan et al., 2010). Broader literature on cancer survivorship attests to the importance of return to work in relation to recovery from the social and financial impacts of cancer (Duijts et al., 2013; Groenveld et al., 2013; Mak et al., 2013; Mehnert et al., 2013; Shankaran et al., 2012).

Research Problem

While the negative impact of disruption to employment and education among AYA cancer patients is well-established in the literature (Choquettte et al., 2016; Georgiadi & Kourkoutas, 2010; Mehnert, 2011; Morgan et al., 2010; Zebrack & Isaacson, 2012), less is known about its longitudinal impact across the vicissitudes of survival for an AYA patient care population that is ever more socioculturally diverse. Over the last decade, the oncology community has increasingly recognized the need for more psychosocial research efforts to shed light on how AYA patients move through employment/education pathways following a cancer diagnosis (Bleyer, 2011; Choquettte et al., 2016; D'Agostino et al., 2011; Georgiadi & Kourkoutas, 2010; Haase & Phillipes, 2004; Mehnert, 2011; Morgan et al., 2010).

Research question and aims. The current study addressed the primary question: How are trajectories of employment/education and psychological distress characterized across two years following a cancer diagnosis among socioculturally diverse adolescent and young adult (AYA) patients, and whether and how is change in occupational status associated with psychological distress over time? Within this overarching question, the researcher pursued two specific aims: (1) To identify longitudinal trajectories of psychological distress among AYA cancer patients across two years following initial cancer diagnosis, and depict the association between psychological distress and treatment status, health status, and sociocultural factors; (2) To examine the relationship between theoretical trajectories of occupational status and psychological distress across two years after initial cancer diagnosis among AYA cancer patients, including examination of treatment status, health status related to readiness to work, and sociocultural factors.

Conceptual Framework

The present research was primarily informed by Giuntoli et al.'s (2015) middle-range theory of the mental health and well-being effects of employment transitions. Giuntoli et al.'s (2015) theorization is middle-range in its consideration of a broad range of individuals' health and well-being factors within one coherent framework, including hedonic well-being (i.e. emotions and life satisfaction), eudaimonic well-being (life functions), psychological well-being and social well-being. The preponderance of prior theoretical work on job loss focuses on fewer or only one of these variables. Building upon extant literature on job loss as a *status passage,* Giuntoli et al. (2015) explain the association between involuntary unemployment and mental well-being by positing that employment transitions are *status passages,* whereby individuals who experience job loss move onto a different rung of the social ladder with the possibility of changed identity, sense of self, and behavior (Ezzy, 1993). Furthermore, these *status passages* are accompanied by health and well-being effects, mental health in particular, that are based on personal and social meanings called *properties of transitions* (Giuntoli et al., 2015).

Figure 1 illustrates a reduced adaptation of Giuntoli et al.'s (2015) theoretical model used in the current study. The path of interest to the current dissertation research is shown, beginning with the independent variable *divestment passage* (unemployment), moving through *disruption of role-based identities,* and ending with the final outcome *hedonic well-being.*

Additionally, the present research drew upon Feuerstein et al.'s (2010) cancer and work model, which describes the association of psychological factors related to work outcomes including symptoms of fatigue, cognitive function, and psychological distress. Although psychological distress is interpreted as an independent variable in Feuerstein et al.'s (2010) model, it remains instructional for the present line of inquiry as it contextualizes the unique experience of cancer patients with various distinct influences. Specifically, Feuerstein et al.'s (2010) cancer and work model represents its primary work outcome in four components – *return to work, work ability, work performance, and work retention,* and further conceptualizes factors in the relationship between cancer and work as *cancer survivor characteristics* – age, gender, race, marital status, socioeconomic status, and ethnicity; *symptoms* – fatigue, cognitive, distress, pain, sleep problems, and dyspnea; *function* – physical, cognitive, emotional, interpersonal; *work demands* – physical, cognitive, emotional, and interpersonal, *work environment* – flexibility, support, climate, job stress, as well as the interplay of macro-level *policies, procedures, and economic factors.* Extant literature confirms the bidirectional nature of the relationship between work and psychological distress, with some empirical studies representing work as the outcome variable (Dorland, 2016; Giuntoli, 2015; Muijen et al., 2013; Spelten et al., 2002), while others naming psychological distress as the outcome variable (Dooley et al., 2003; Marchand et al., 2005; Munir et al., 2007).

Overview of Study Design and Methods

To ensure the most complete examination of the complex set of research questions raised by the previously stated research question and aims, descriptive, bivariate, and multivariate analyses using linear mixed-effects models were employed in the present dissertation research. The HopeLab longitudinal dataset was utilized (Zebrack et al., 2013). The dataset consists of 215 adolescent and young adult (AYA) cancer patients ages 14-39 years collected at four time points: baseline (within 4 months of diagnosis), 6 months following diagnosis, 12 months following diagnosis, and 24 months following diagnosis; collected from three institutions: University of Southern California/Children's Hospital Los Angeles, University of Texas Health Science Center at San Antonio, and Oregon Health and Science University.

Significance of Study

Building upon extant literature, the present dissertation research advances the evidence base with empirical findings on trajectories of employment and education among socioculturally diverse AYA cancer patients and their relationship to psychological distress. To the best of the researcher's knowledge and despite burgeoning interest in AYA cancer patients, no known study to date has examined the impact of disruption to employment and education on psychological distress across a period as long as two years following a cancer diagnosis for this socioculturally diverse population. Furthermore, although the mental health benefits of work are well documented, whether and how this relationship applies to AYA cancer patients is less known. In light of the aforementioned psychosocial issues related to the disruption of work/school roles being integral to AYA cancer patients' daily lives and future prospects, the current dissertation research makes a unique contribution to the literatures of psychosocial oncology, health, and behavioral health, generating findings that are of clinical, practical, and intellectual importance.

CHAPTER 2

LITERATURE REVIEW

Introduction

The following review of the literature presents extant findings and gaps in knowledge that are relevant to the current study of occupational status changes and psychological distress among adolescent and young adult (AYA) cancer patients. First, the researcher uses evidence on occupational status changes to articulate possible trajectories of employment and education among AYAs. Second, the salience of psychological distress among AYAs is explicated within a conceptual framework. Third, factors related to the relationship between occupational status change and psychological distress for young cancer patients are described within a conceptual framework. Lastly, the researcher summarizes previous research on AYA cancer patients using the Hopelab longitudinal dataset (Zebrack et al., 2013), and makes the case for further inquiry.

Trajectories of Employment & Education in AYA Patients

The adolescent and young adult years are a transitional time in which young people's actions and decisions related to employment and education constitute the foundation for future income and career goals across the remaining balance of their lives (Arnett, 2000; Chisholm & Hurrelmann; Craig 2006). According to Arnett (2014), occupational trajectories among emerging adults in their late teens and early twenties are highly diverse, with various levels of engagement in employment and/or education roles, calling attention to regional patterns unique to the U.S., Europe, and Japan. Arnett (2000) describes school attendance among emerging adults as often pursued in a non-linear way with starts, stops, and periods of partial participation that may be combined with employment. This high level of instability does not lessen until the late twenties when more enduring occupational choices are made (Arnett, 2000). For AYA cancer patients, the disruption of cancer exacerbates an already occupationally disruptive period.

Disrupted by a cancer diagnosis, AYA cancer patients follow five known trajectories of occupational status change that are supported by extant literature – i.e. engagement and disengagement from work/school roles across time (Choquette & Rennick, 2016; Duijts et al., 2013; Grinyer 2007; Spelton et al., 2002; Mak et al., 2013; Mehnert et al., 2013; Moran et al., 2011; Nellis, 2012; Zebrack et al., 2014). Figure 2 illustrates these five possible occupational trajectories. AYA cancer patients in the current study, who may be described by trajectories 1 and 2, stop work/school at some point within the first 6 months following a cancer diagnosis. Those in trajectory 1 returned to work/school by 24 months following diagnosis, whereas those in trajectory 2 did not. For AYAs who are described by trajectory three, they were occupied with work/school just before a cancer diagnosis, continue work/school for at least six months following diagnosis, then stopped work/school within the first 2 years following diagnosis. Lastly, for AYA cancer patients in this study who may be described by trajectories four and five experienced no changes in occupational status across the period of observation – specifically, they were either occupied or not occupied with work/school just before their cancer diagnosis and remained occupied or not occupied, respectively.

Evidence demonstrates that AYA patients who maintain work and school roles following a cancer diagnosis experience positive impacts on future occupational prospects and improvements in quality of life outcomes, reduced social isolation, and increased self-esteem (Barofsky, 1989; Peteet, 2000; Spelten et al., 2002). Husson and Zebrack's (2016) study of the impact of cancer among 173 AYA cancer patients diagnosed between ages 15-35 years, found that being employed was associated with increased positive impacts of cancer, whereas being unemployed was associated with increased negative impacts. Taken together, these findings suggest that continued engagement in employment and education is credited with providing AYA cancer patients a sense of identity, self-worth, source of income, and requisite health insurance for clinical treatment and follow-up (Bradley & Bednarek, 2002; Ganz, 1990; Hays, 1993; Spelton, 2002; Nachreiner et al., 2007). AYAs with a history of cancer, however, report problems maintaining and reintegrating back into work and school roles following cancer (Helms, 2014; Parsons, 2012; Spelten, 2001), calling for closer study.

Employment challenges among older AYAs. As previously mentioned, one prevailing challenge among AYA cancer patients is that the disruption of cancer comes during a developmental life stage when frequent job changes, unstable employment, and newly established and changing careers are the norm (Arnett, 2007). A cancer diagnosis may delay achievement of employment and career goals, and contribute to increased social isolation and decreased self-esteem (Morgan et al., 2010). Nonetheless, Arnett (2007) suggests that emerging adults are seemingly unwilling to compromise their aspirations for employment that offers both adequate compensation and a satisfying identity fit, which complicates job challenges.

Cancer and its side effects can be a career setback for AYAs, with demonstrated effects on employment long after the initial period of treatment and recovery (Moran et al., 2011; Nellis, 2012). Moskowitz and colleagues' (2014) cross-sectional study of cancer patients ages 18-74 years who had completed primary cancer treatments (n=1,525), reported that losing or quitting a job because of cancer was attributed to lower levels of work ability and workplace problems. Poor treatment, discrimination, being passed over for promotion, and lack of accommodations were directly related to the ability to work (Moskowitz, 2014). Feuerstein et al. (2010) argue that work ability, work performance, work retention, and return to work are patient outcomes influenced by an array of factors including individuals’ socio-demographics, current financial climate, workplace organizational culture, work environment, job demands, as well as patients’ physical health and mental functioning. Cooper et al.’s (2013) 12-month retrospective study of return to work in a sample of 290 patients (mean age of 55 years), found differences by type of cancer. Breast cancer patients took the longest to return to work (median 30.0 weeks) followed by head and neck patients (median 18 weeks) and gynecological patients (median 18 weeks), and urology patients returned to work soonest (median 5.0 weeks) (Cooper et al., 2013).

Although there is a lack of evidence focused on the workplace issues of AYAs, the return to work literature discusses such challenges for the broader cancer patient population. Namely, extant findings show that co-workers’ attitudes, employer accommodations, workplace discrimination based on cancer status, and patients’ self-appraisals of work ability are important factors in cancer patients’ experiences of returning to work.

In a review of the literature on cancer patients’ return to work and employment status, Muijen et al. (2012) found studies with strong evidence that physical exertion, less invasive surgery, chemotherapy, and cancer site were factors that predicted patients’ return to work, and that employment was predicted by age, education, and income. Additionally, Spelton et al.’s (2002) review of the literature on factors influencing the return to work for cancer survivors identified evidence that a supportive work environment facilitates a return to work; work that requires physical effort is negatively associated with return to work, as well as mixed results as to whether increasing age is a hindrance to return to work. At the same time, some evidence indicates that in this population, a positive attitude from co-workers is also associated with return to work (Ehrmann-Feldman et al., 1987).

According to Bouknight et al.'s (2006) study on return to work following breast cancer, patients' perceptions of *employer accommodations for cancer and its treatments* as well as perceptions of *employer discrimination related to a cancer diagnosis* were independently associated with return to work at 12 months after a breast cancer diagnosis, controlling for patients' demographic characteristics, health status, cancer stage, treatment, and job type. In terms of work ability, De Boer et al.'s 2008 prospective study of cancer patients included a heterogeneous mix of cancer diagnoses, and found that patients underscore the importance of self-assessed work ability in the process of returning to work, independent from age and clinical factors. Findings showed that cancer patients who received chemotherapy and/or had hematological cancers had the lowest work ability scores, whereas patients diagnosed with gastrointestinal or urogenital tract cancers had the highest work ability scores (De Boer et al., 2008).

Educational challenges among younger AYAs. One in five childhood cancer survivors have been found to repeat a grade (Barrera et al., 2005). Although pursuing education is not delimited by age, school attendance for younger AYAs is not only important for timely matriculation through education programs; it also promotes a sense of normalcy in the face of an abnormal illness (Choquettte et al., 2016; Georgiadi & Kourkoutas, 2010). Attending school can facilitate AYAs' ability to sustain both connections with peers and participation in important social events/milestones; these connections are critical to obtaining age-appropriate social skills and preventing the loss of friendships (Morgan et al., 2010). Furthermore, in Searle et al.'s (2003) qualitative study of continuing education among on-treatment adolescent cancer patients ages 12-17, home-based learning was found to be less favorable than community or hospital learning environments.

According to Helms et al.'s (2014) meta-analysis on school re-entry and peer acceptance of children with cancer, perceived peer support in the school environment strongly predicts positive psychosocial development outcomes (Benner & Marlow, 1991; Delong, 1999; Treiber et al., 1986). This is reinforced by evidence that young cancer patients, who feel they have good social reputations, have better social functioning than comparable peers without a history of cancer (Noll et al., 1999). Lack of peer acceptance at school is a major barrier to attendance (Helms, 2014), and avoidance of school has been attributed to bullying of young cancer patients in school settings (Wasserman et al., 1987). Parsons et al.'s (2012) population-based cohorts study of 463 recently diagnosed cancer patients between ages 15-39 found that AYA cancer patients exhibit lower performance in work/school compared to their healthy peers, with self-reported problems with "forgetting" in 50% of respondents and trouble "keeping up with work or studies" in 30% of respondents. Prior studies have also identified associations between work/school participation, physical limitations, chronic fatigue, and issues with cognitive function such as concentration (Bonneau et al., 2011; Bouknight et al., 2008; Curt, 2001; Hoving et al., 2009; Kearney, 2008; Pryce et al., 2007).

Psychological Distress is a Critical Issue for AYA Cancer Patients

Cancer during the AYA years is a particularly threatening and powerful life event that is typically not well-tolerated in terms of psychological distress (Thornes, 2002; Singh & Hodgson, 2011). AYA cancer survivors are more likely to experience mental distress than their counterparts without cancer (Kaul et al., 2016). In their review of the literature on the psychosocial needs of adolescents with cancer, Singh and Hodgon's (2011) explain that cancer accentuates and adds new dimensions to young patients' anxieties, such as fear, uncertainty, restrictions in daily life, increased psychological and physical work, and lengthy and rigorous treatment regimes. AYAs are still growing in cognitive capacity, emotional maturity, and social skills, so they often do not have the necessary capacity and skills to cope with the demands of a cancer diagnosis on their lives (Palmer et al., 2014). When cancer is experienced during the AYA life stage, resentment and anger can result from the developmental regression that is a typical response to any major illness (Self, 2005), and such heightened emotional responses can have negative impacts on adherence to medical advice and treatments (Butow, et al., 2010).

Psychosocially, AYA cancer patients face a range of practical, emotional and social problems that are intensified by their life stage, even as they are suddenly called to survive cancer amidst the usual developmental turmoil and instability of adolescence and early adulthood (Bleyer, 2002). Some biopsychosocial issues in AYA cancer survivorship include disruptions in school or work, changes in physical appearance, increased dependence on parents, financial challenges, loss of reproductive capacity, premature confrontation with mortality, and health-related concerns about the future (Zebrack et al, 2013). According to Bellizzi et al.'s (2012) study on the psychosocial impact of cancer on newly diagnosed AYAs, respondents indicated negative life impacts in regards to the appearance of their body, control over their lives, plans for education, plans for work, relationship with spouse/significant other, friendships, plans for having children, and sexual function/intimate relationships. AYA cancer patients must simultaneously resolve the typical conflicts of normal psychosocial development with the anomalous trauma and persistent challenges of life-threatening illness. For example, in adolescence, cultivating a coherent self-identity is instrumental to a strong sense of self worth in young adulthood (Brinthaupt & Lipka, 2002), and a diagnosis of cancer induces psychological distress that may disrupt this trajectory.

Bonanno's (2004) stress-coping model (Figure 2) is the conceptual framework used in the current study to characterize trajectories of psychological distress experienced by AYAs after a cancer diagnosis. According to Bonanno's, psychological resilience is a salient protective factor in how an individual responds to trauma. This model distinguishes itself from previous models by elucidating a balance of positive and pathological coping pathways. Represented by four possible coping trajectories, AYAs in the first trajectory, *chronic*, are described by a persistent severe stress response across time, whereas the *delayed* trajectory suggests a delay in reporting stress symptoms, the *recovery* trajectory indicates an improvement of stress symptoms over time, and finally, the resilient trajectory is described by a persistently mild to moderate response to distress across time.

Factors Influencing Occupational Status Change

As mentioned in the background chapter (pp. 13-15), the present research was primarily informed by a reduced adaptation of Giuntoli et al.'s (2015) middle-range theory of the mental health and well-being effects of employment transitions (Figure 1). Furthermore, the present research focuses on cancer-specific factors related to work outcomes as identified by Feuerstein et al.'s (2010) cancer and work model.

Health Status – Fatigue and Cognitive Function. Extant literature is rich with evidence on fatigue and cognitive function as the most prominent health status symptoms challenging cancer patients who contend with return to occupational roles following a cancer diagnosis (Dorland, 2016; Giuntoli, 2015; Moskowitz et al., 2014; Muijen et al., 2013; Spelten et al., 2002). AYA cancer patients' experiences of persistent fatigue and cognitive problems challenge necessary reintegration into employment and education pathways during a critical developmental life stage for pursuing foundational education and early career goals.

Cancer-related *fatigue* is defined as a lasting subjective feeling of physical, emotional, or intellectual exhaustion, which cannot be explained by previous activities, such that severe exhaustion compromises the patient's everyday life (Behringer et al., 2016). According to Behringer et al.'s (2016) longitudinal study of 5,306 Hodgkin's lymphoma survivors with a median age of 34 years, the persistence of severe fatigue was found to have a significant negative relationship with employment that endured for up to nine years following a cancer diagnosis. Also, significantly fewer cancer patients who reported severe fatigue were engaged in full- or part-time work or education compared to their counterparts without fatigue (Behringer et al.'s, 2016).

Cognitive function refers to deficits in intellectual processing that are common among cancer patients, and is a symptom attendant to cancer and/or its treatments (Dorland, 2016). The existence of cognitive problems among adult cancer patients following diagnosis and treatments is well-evidenced in the literature, but few studies focus on AYA cancer patients (Ahles et al., 2012; Reid-Arndt, 2010; Vardy, 2009; Wefel & Schagen, 2012). In Chan et al.'s (2016) call for evidence, the authors raise awareness for more empirical investigation into the experience of "chemobrain" and other cognitive toxicity among AYA cancer patients, suggesting that existing studies on adult cancer patients can not be applied to AYAs whose biomedical and psychosocial experiences and needs greatly differ. In the context of work/school, cognitive problems with memory, attention, and concentration influence occupational performance and gainful productivity. According to the Adolescent and Young Adult Health Outcomes and Patient Experience (AYA Hope) study, over 53% of AYA cancer patients reported problems with "forgetting" at 15–35 months after a cancer diagnosis and one-third of these study participants finding it "difficult to pay attention at work or school" (Parsons et al., 2012). In Guy et al.'s

(2014) study of the health and economic burden of cancer on 1,464 AYA cancer patients, AYAs were found to be at heightened risk for lost work productivity compared to adults without a history of cancer, with excess annual productivity losses of $2,250 per person.

Multifaceted Sociocultural Diversity Among AYAs. An understanding of AYA cancer patients also demands an understanding of the multifaceted sociocultural contexts in which they cope with the burden of cancer. AYA cancer patients are a heterogeneous mix of age cohorts, developmental stages, socioeconomic statuses, and personal identities that influence AYAs' knowledge, attitudes, beliefs, and subsequent cognitive, behavioral, and attitudinal responses to cancer (e.g., adherence to therapy, use of alcohol/drugs, social involvement, ability to manage treatment side effects).

Extant literature on AYAs suggests that a sociocultural perspective may contribute to improvements in survivorship outcomes for AYAs, particularly for AYA patients who may be marginalized as a result of their social or cultural identities–such as racial/ethnic, socio-economic, and gender identity–and thus not adequately or appropriately served. According to Sender and Zabokrtsky (2015), it has long been recognized that incidence of cancer and responses to its treatments vary by gender, ethnicity, and race among AYAs. The present research prioritized sociocultural views by including consideration of AYA cancer patients’ age, gender, race/ethnicity, live alone status, and geographic location.

Chronological age and cohort effects. The current cohorts of AYAs are grouped into Gen Y Gen X based on soft boundaries of chronological age – AYAs in their teens through 20s are Gen Y, and those in their 30s are Gen X (Yang, 2008). A cohort is defined as a group of people who share the experience of an initiating event, such as birth, marriage, or cancer diagnosis, in the same year (Yang, 2008). Not to be confused with age effects that are endogenous, aging-related developmental changes, cohort effects are exogenous temporal trends across a given time period that are experienced by its members (Yang, 2008). An understanding of Gen X and Gen Y cohort effects adds contextual detail to depictions of the environments in which AYAs cope with the disruption of cancer, even though AYAs' self-identity cannot be subsumed by these broad generational categories.

For example, in recent decades, doubts have surfaced about whether education actually results in substantive positive social and economic outcomes for young people. Evidence revealed biases in education systems that select who continues and who does (Hout, 2012). Rebutting this criticism of higher education, Hout's (2012) review of the literature on the social and economic returns of college education found numerous studies supporting the claim that college graduates find better jobs, financial earnings, and suffer less unemployment than high school graduates. College graduates were also found to enjoy more stable family lives, better health, greater longevity, and were significantly more likely to say they are "very happy," compared to high school graduates (Hout, 2012).

At the younger end of the age spectrum, the present cohort of AYAs in their teens and early 20s were just beginning to test the boundaries of newfound autonomy and feelings of invincibility, when they were interrupted by a diagnosis of cancer. Born roughly between the early 1980s and early 2000s, they make up a generation referred to in popular media as Gen Y, Millenials, Echo Boom, Trophy Kids, and No Collar Workers; accused of being "the new American idle" (Graham, 2013) and needing "more subsidies than a dairy farmer" (Howe & Strauss, 2009). In his book focused on how the Millenial generation is entering and shaking up the workforce, Alsop (2008) makes some acerbic commentary about these young workers. For example, Alsop (2008) describes Millenials as broadly unaccustomed to personal criticism, due in part to growing up receiving trophies for putting forth any amount of effort regardless of who wins, so as not to damage anyone's self-esteem. On a more positive note, Pew Research Center (2010) depicts this cohort as self-confident, connected, and open-to-change, with pervasive technology use as the defining characteristic of Millenials, when compared to the generations that came before them – Gen X, Baby Boomers, and the Silent Generation. They are assumed to get along well with their parents, are economically optimistic about their futures despite low employment rates after great investments in higher education, and they require your immediate attention; this latter characteristic owing to their constant connectivity to social media, digital technology, and bottomless sources of instantaneous information (Alsop, 2008; Pew Research Center, 2010; Schawbel, 2012).

At the older end of the spectrum, AYAs in their late 20s and 30s are beginning to realize some of their life goals in terms of family and career, when a diagnosis of cancer disrupted their lives. They may be the same age or older than the new medical residents, fellows, interns, nurses, and social workers, who are being trained on their bodies. Born roughly between 1980 and 1964, Generation X also carries the moniker, "America's neglected middle child," owing to its overlooked status between the much larger generations of Baby Boomers and Millenials (Taylor & Gao, 2014). Gen Xers were called slackers and aimless in the 1990s, and then subsequently forgotten (Luhby, 2014). In more recent years, Gen Xers are profiled as savvy, skeptical, self-reliant, and unconcerned with the social pressures of what others think of them or even if they're thought about at all (Taylor & Gao, 2014).

Generational stereotypes about AYAs may hint at certain remarkable features about how society perceives an age cohort, but they are not to be relied upon heavily or singularly in practice. However, some knowledge of common societal assumptions about AYAs may help anticipate possible stressors faced by AYA cancer patients, who are a subset of a stereotyped generation ascribed upon them by the dominant culture.

Gender identity. Beginning in early adolescence, the sociocultural influence of gender roles and expectations intensifies, requiring the individual to make personal adjustments that affect the formation of self-esteem, self-competency, and perceptions of the physical, sexual, and social self (Basow & Rubin, 1999). An abundance of extant research confirms that depression rates rise dramatically during adolescence, with a gender difference indicating more depressed females than males that persists throughout adulthood and across many different countries and cultures (Hankin & Abramson, 2001). After the age of 15, females are nearly twice as likely to be depressed as males; although the mechanism of this onset is less known, this gender difference is well-established (Steinberg & Morris, 2001; Nolen-Hoeksema & Girgus, 1994). Working knowledge about the influence of gender as a possible risk factor for depression and other symptoms of emotional distress can help providers to better understand the added developmental stressors on AYA cancer patients. High level of emotional distress is a risk factor for non-adherence to cancer therapy among AYA cancer patients, which can lower their chances of survival (Butow, 2010).

Racial/ethnic identity. Although race is not biologically defined (American Anthropological Association, 1998; Goodman, 2000), but rather, a social construct that is an unclear mix of self-identification and societal perceptions; it remains a central concept in American life. Membership in a marginalized racial and/or ethnic minority group presents AYAs who are still forming their sense of identity with a choice: either accept the negative views of society toward their group or reject the dominant perspective and search for their own identity (Breakwell, 2015; Tajfel, 1978). If AYA internalize the negative views of the dominant society in the process of resolving oppositional self-identities, they can develop a negative identity and self-hatred (Cote, 2014; Ecclest et al., 2006; Phinney, 1991; Phinney, 1989). For members of oppressed and exploited minority groups, ethnic self-identity is central to the development of a positive psychosocial adjustment (Gummadam et al., 2016). In Marcia's (1980) heavily cited theorization of an ethnic identity paradigm in adolescence, matriculation through four identity statuses is essential. These four identity statuses are based on the presence or absence of personal exploration and commitment – diffuse identity, foreclosed status, moratorium, and achieved identity, culminating in attainment of the final achieved identity as a result of an identity crisis where exploration leads to clear commitment (Marcia, 1980).

To the best of the researcher's knowledge, the presence or absence of *white privilege* among White and Non-White AYA cancer patients, and how such benefits relate to health outcomes has not been documented as such within the psychosocial oncology literature. White privilege refers to the benefits of White racial identity that places such individuals at an advantage (McIntosh, 1988). Even though race is a prominent construct in the interest of reducing disparities in health care, the focus of investigation is most often on negative outcomes of (Non-White) racial minorities (Hunt et al., 2013). Race remains a controversial topic within medicine, where health care providers must weigh the benefits of including patients' racial identity in clinical practice (Nawaz & Brett, 2009; Chin & Humikowski, 2002; Smedley, 2002), and the risks of racial stereotyping that may increase disparities (Acquaviva & Minz, 2010).

Extant literature has shown association between minority racial status and worse mental health outcomes among young people (Lopez et al., 2016; Priest et al., 2013; Stein et al., 2016). Lopez et al.'s (2016) study of racial/ethnic differences in trauma exposure and mental health disorders found less delinquency following experiences of trauma among Non-Hispanic White adolescents compared to Non-Hispanic Black and Hispanic White adolescents. Additionally, Stein et al. (2016) revealed that self perceptions of racial/ethnic discrimination played a significant role in the development of depressive symptoms among African American and Latino high school students (n=155).

Live alone status. According to Arnett (2000) the living situation of emerging adults is highly variable with instability and frequent changes that bookend periods of independent role exploration – e.g. entering or leaving college; starting or ending a new job. During these periods of exploration, separation from family and the taking on of personal responsibility are the norm for psychosocial growth and development during the AYA years (Arnett 2000; Self, 2005). For younger AYAs, greater dependence on family members contradicts their developmental struggle for greater autonomy; whereas, for older AYAs who move back in with parents, the loss autonomy is often coupled with the loss of financial freedom, as they may have attained some degree of financial independence before the disruption of cancer (Grinyer, 2007).

Cohabitation with romantic partners is less often observed in young people with a history of cancer than their counterparts without cancer. Evidence shows that survivors of cancers diagnosed in childhood are less likely to be married or cohabitate compared to their same age peers, with a significantly high proportion of young male survivors living with parents (Langveld et al., 2003). Langveld et al. (2003) suggest that these findings indicate dislocation from normal developmental acquisition of autonomy that may perhaps be repercussions of dependency on parents during illness. Due to the child's former illness, an unusually strong and perhaps maladaptive bond may develop between parent and child to the extent that they are exclusively reliant on each other to satisfy emotional and physical needs (Langveld et al., 2003).

Geographic location. Where an AYA receives cancer care is an indication of access to specialized cancer care including cancer treatments, clinical trials, and psychosocial programs and services. For the most part, AYA cancer patients receive cancer treatments in either pediatric or adult settings that are not designed to capture their unique needs, and the referral of AYAs to either pediatric or adult treatment settings is inconsistent and arbitrary (Zebrack et al., 2010). The international oncology community's acknowledgment of the need to improve lagging outcomes for AYA cancer patients has led to vigorous debates about optimal health care settings (Thomas et al., 2006). As it stands, AYA cancer patients have limited access to specialized cancer care providers, appropriate psychosocial resources, and clinical trials (Albritton & Bleyer, 2003; Cheung & Zebrack, 2016; Thomas et al., 2006; Zebrack et al., 2009). According to Sateren et al.'s (2002) large study on accrual to clinical trials among 24,332 cancer patients, pediatric patients had the highest observed accruals to clinical trials, whereas for adolescent and older patients, only a small percentage were enrolled in clinical trials. Additionally, geographic locations with higher socioeconomic levels had higher levels of clinical trial accruals with the highest accruals in suburban areas (Sateren et al., 2002).

Household income. Zafar and Abernethy (2013) coined *financial toxicity* to describe the patient-level impact of the cost of cancer care, which they attributed to a health care context in which: 1) cancer treatments are increasingly more expensive, (2) expensive treatments are over-utilized by providers, and (3) these rising costs are passed onto patients as out-of-pocket expenses. Furthermore, the authors explain that similar to physical toxicity, the financial toxicity can prevent access to optimal cancer care and diminish quality of life. Moreover, both objective experiences of financial burden and subjective experiences of financial distress are key, and should be considered (Zafar & Abernethy, 2013). Pisu et al.'s (2015) study of racial minority and non-minority cancer patients found that at one year following cancer diagnosis, approximately 50% of cancer survivors experienced economic hardship as evidenced by inadequate housing, food, or medical attention. The authors also found that African American patients were more likely to experience economic hardship (Pisu et al., 2015).

For AYA cancer patients, out-of-pocket expenses for treatment and follow-up care may be further challenged by the influence of unstable labor markets and frequent changes in occupational status, that are already a common feature of AYAs' transitional life stage (Hammond, 2016). In combination, these influences make it more difficult for AYAs to secure employer-sponsored health insurance benefits to assist with the financial sequelae of cancer (Swanberg et al., 2017).

Previous Research

While contributing to the aforementioned findings from the psychosocial oncology, health, and behavioral health literatures, the present research also expanded upon preceding studies using the Hopelab longitudinal dataset (Zebrack et al., 2013).

First, Kwak et al.'s (2012) one-year follow-up study of the Hopelab data (Zebrack et al., 2013) investigated the prevalence and predictors of post-traumatic stress symptoms (PTSS) in AYA cancer survivors reported 39% of participants at six months and 44% of participants at 12 months had moderate to severe levels of PTSS, and 29% had PTSS levels indicating post-traumatic stress disorder. Factors associated with higher PTSS levels at 12 months were currently receiving treatment, having surgical treatment, diagnosis of a cancer type with a 90–100% survival rate, remaining unemployed/not in school, and greater PTSS at 6 months.

Second, Kwak et al.'s (2013) one-year longitudinal study of the HopeLab longitudinal dataset (Zebrack et al., 2013) examined trajectories of psychological distress in AYA cancer patients. Findings showed that AYA cancer patients, on average, experienced distress symptoms exceeding population norms at the time of diagnoses, then decreased at the six-month follow-up, but increased to exceed populations norms at the 12-months after diagnosis. Emphasizing the importance of early psychosocial intervention for distress AYAs', Kwak et al. (2013) found an overall decline in psychological distress over time that was primarily a function of being off treatment and involved in school or work. The present research expands upon these previous findings on psychological distress by expanding the study period to include two years of follow-up data.

Third, Zebrack et al.'s (2013) study of psychosocial service use and unmet need among recently diagnosed AYA cancer patients examined the same study sample as the present research. Findings indicated that AYA cancer patients ages 20 to 29 years were significantly less likely than teens and older patients ages 30 to 39 years to report using professional mental health services and were significantly more likely to report an unmet need with regard to cancer information, infertility information, and diet/nutrition information (Zebrack et al., 2013). Additionally, in comparison to teens who were treated in pediatric facilities, AYAs who were treated in adult facilities were more likely to report an unmet need for age-appropriate Internet sites, professional mental health services, camp/retreats programs, transportation assistance, and complementary and alternative health services (Zebrack et al., 2013).

Fourth, Zebrack et al.'s (2014) investigation identified trajectories of clinically significant levels of psychological distress throughout the first year following diagnosis, and made use of Bonanno's (2004) stress-coping model. By applying Bonanno's (2004) four trajectories of coping responses following a traumatic event – *chronic, delayed, recovery, and resilient* –

Zebrack et al. (2014) highlighted the importance of resilience as a psychological coping factor among AYA cancer patients.

More specifically, Zebrack et al.'s (2014) findings indicated that 12% of AYAs had clinically significant chronic distress across the 12 months following diagnosis and 15% had a delayed distress response. Additionally, substantial proportions of respondents reported unsatisfied psychosocial service needs at 12 months following diagnosis including needs for information (57%), counseling (41%), and practical support (39%); unmet counseling needs, particularly professional mental health services, was significantly associated with psychological distress over time (Zebrack et al., 2014).

Fifth, Zebrack et al.'s (2015) investigation of the relationship between posttraumatic stress symptoms and posttraumatic grown in AYA cancer patients across two years following diagnosis, examined the same data that was used in the present research. Curvilinear relationships between a posttraumatic stress symptom of re-experiencing and two of five posttraumatic growth indicators (New possibilities, Personal strengths) were observed (Zebrack et al., 2015). However, there were no significant relationships between overall posttraumatic stress severity and posttraumatic growth (Zebrack et al., 2015).

Lastly, Husson et al.'s (2017) study on social functioning and Husson et al.'s (2017) study on health-related quality of life (HRQoL) both examined AYA cancer patients utilizing the Hopelab longitudinal dataset. Results showed that although improvements were observed over time for social functioning and HRQoL, both were still compromised at 24 months following cancer diagnosis.

The current study contributes new knowledge by building upon the aforementioned previous research to elucidate understanding of how trajectories of employment/education and psychological distress are characterized across two years following a cancer diagnosis, and whether and how change in employment/education status is associated with psychological distress across two years following cancer diagnosis for socioculturally diverse adolescents and young adults.

Based on the findings surfaced by this review of the literature, the state-of-the-art in research on long-term survivorship from AYA cancer appears to suffer from scarcity about the myriad of psychosocial factors related to their occupational engagement and mental health. Recently emerging interest in studying AYA cancer survivorship lends itself to greater empirical investigation, thereby building a solid foundation of evidence needed to explain the undisputed presentation of poor outcomes among this patient care population.

CHAPTER 3

METHODS

Introduction

This chapter describes the methods the researcher utilized to investigate whether and how the disruption of a cancer diagnosis impacts trajectories of employment and education across two years following a cancer diagnosis for socioculturally diverse AYA cancer patients. First, the researcher opens by re-stating the overarching research question, hypotheses, and aims. Second, the linear mixed-effects research design is explained. Third, the data source, study sample, and variables and measures are described. Fourth, the analysis plan to address each of the study aims is articulated. In closing the chapter, the researcher addresses ethical and cultural considerations.

Research Question

The primary question that this dissertation research investigates is how trajectories of employment/education and psychological distress are characterized across two years following a cancer diagnosis among socioculturally diverse AYA patients, and whether and how change in occupational status is associated with psychological distress over time.

Hypotheses and Aims

The current study examined the following aims and respective hypotheses. Keep in mind that aim one was an exploratory study, primarily compelled by the goal of characterizing trajectories psychological distress:

Aim one. To identify longitudinal trajectories of psychological distress among AYA cancer patients across two years following initial cancer diagnosis, and depict the association between treatment status, health status, and sociocultural factors and psychological distress trajectories (Figure 3), according to Bonanno’s (2004) Stress-Coping Model (Figure 2).

Hypothesis one. Being on-treatment will have a positive association with psychological distress across time, controlling for health status, and sociocultural factors.

Aim two. To examine the relationship between theoretical trajectories of occupational status and psychological distress across two years after initial cancer diagnosis among adolescent and young adult cancer patients, including examination of treatment status, health status related to readiness to work, and sociocultural factors (Figure 7).

Hypothesis two. Occupational Status Trajectory One (*stopping work/school* within the first 6 months after cancer diagnosis and *returning to work/school* within 24 months) will be associated with decreased psychological distress measured at 24 months, i.e. resilient psychological distress trajectory, according to Bonanno's (2004) Stress-Coping Model.

Research Design: Linear Mixed-Effects Models

In order to adequately answer the primary research question and its two aims, the researcher pursued a quantitative research design by employing linear mixed-effects models. Linear mixed-effect models were best suited for analyses, because responses in the Hopelab longitudinal study (n=215) are measured at "multiple, but not too many time points (Czado, 2004). Data in the current study were collected at three of the four available time points within the Hopelab dataset: baseline (within 4 months of diagnosis), 6 months, and 24 months following a cancer diagnosis. Since multiple responses to self-reported measures of psychological distress from each AYA participant were considered, the independence assumption of linear models is violated, as repeated measures of psychological distress in the same AYA participant are interdependent (Rabe-Hesketh & Skrondal, 2008). Likewise, there was interdependence between response items provided by each AYA participant. For example, the type of cancer treatment and health status are interdependent. Further extending the linear model to allow for dependence, the linear mixed-effects model for analyses included both fixed effects and random effects (Hedecker & Gibbons, 2006). In the current study, the linear mixed-effects model allowed for mixing the main fixed effect of occupational status trajectory and psychological distress with random effects. Random effects included the time-invariant variables: gender, race, and geographic location; as well as time-variant variables: live alone status, treatment status, fatigue, cognitive function, and their respective interactions with the time point. Hence, random intercepts for each random effect were added to each fixed effect (Hedecker & Gibbons, 2006).

In this research, a fixed effect was a covariate such as age, whereas a random effect is a variable whose levels are randomly sampled from the study population, such as observed levels of random effect "income." Data in the current study included both fixed effects and random effects, as it consists of responses across time from the same subject regarding perceptions of psychological distress symptoms that may be related to a previous response. An important advantage of using a linear mixed model over other longitudinal approaches, such as repeated measures ANOVA, for the present research, was that linear mixed-effect models allowed for the inclusion of subjects with incomplete data across time, i.e. missing data (Hedecker & Gibbons, 2006). Data in the current study contained missing values in response to certain items at certain time points for AYA participants.

Data Source

Analyses for the present study utilized the HopeLab longitudinal dataset, compiled by Zebrack and colleagues (2013) at data collection sites that included three pediatric care centers: Children's Hospital Los Angeles in Los Angeles, California; Doernbecher Children's Hospital in Portland, Oregon; The Children's Hospital of San Antonio in San Antonio, Texas as well as two adult care centers: Oregon Health and Science University Hospital in Portland, Oregon and

Cancer Therapy and Research Center at the University of Texas Health Science Center at San Antonio in San Antonio, Texas. Institutional review board approval was obtained from each participating institution and care center.

Between March 2008 and April 2010, research staff at each participating institution invited 286 eligible patients to participate in the study, based on information from clinic registration rosters. Informed consent and/or assent was obtained from patients and their parents. Additionally, physician approval was secured before each patient was approached for study participation. Of the 286 eligible patients, 58 patients did not participate either due to their own refusal or a physician’s denial and recommendation that these patients were too sick to participate. Of the remaining 228 patients, 13 did not return a baseline survey following consent, with one of these due to the patient’s death. The final sample (n=215) of the Hopelab longitudinal dataset (Zebrack et al., 2013) resulted from a participation rate of 75% (Table 1).

Eligibility criteria. Eligible patients were between ages 14 to 39 years, first diagnosis of any form of invasive cancer within the last four months, and proficient in reading and comprehending English or Spanish. The AYA age range of 14-39 years used in the study was consistent with the National Cancer Institute’s Adolescent and Young Adult Oncology Progress Review Group (Smith et al., 2016). The eligibility first diagnosis within the last four months was established in consideration of referral patterns in which AYA patients may receive their initial cancer diagnosis at a community clinic and then transferred later for further staging and treatment.

Data Collection. Participants completed self-administered questionnaires at each of the four time points used in this study: within four months of a cancer diagnosis, six months following diagnosis, 12 months following diagnosis, and 24 months following diagnosis.

Questionnaires captured responses to independent variables: occupational status change, employment status, treatment status, and sociocultural participant characteristics, as well as the dependent variable: psychological distress.

Two-year observation period. Although a five-year period of study would conform to the oncology convention of long-term cancer survivorship and allow for greater opportunity to observe long-term changes, the research examined data collected across two years. Despite this difference, observing the first two years after diagnosis remains useful due to the rare occurrence of securing this unique longitudinal dataset of employment/education data and related psychological distress outcomes among a socioculturally diverse sample of AYA cancer patients. To the researcher's knowledge, no known study to date has examined the impact of disruption to employment and education on psychological distress across a period as long as two years following a cancer diagnosis for AYA patients inclusive of sociocultural factors.

Study Sample

Although the original study (n=215) collected data at the aforementioned four time points – baseline, 6 months, 12 months, and 24 months – self-reported health status data on the experience of fatigue and cognitive dysfunction were not collected from any participants at the 12-month follow-up. All four time points were included in descriptive and multivariate analyses. However, due to issues with missing data, only three time points were included in multivariate analyses: baseline, 6-month follow-up, and 24-month follow-up.

Missing Data

Data Missing Not at Random. Prior to removing all data collected from the third time point from the current study, a bar graph (Figure 4) was produced to reveal general patterns of change in time-variant variables of interest across the two-year study period – specifically, the time-variant variables live alone status, fatigue, cognitive function, and treatment status. The bar graph illustrates that by dropping the 12-month time point, no directional change would be missed for the variables fatigue, cognitive function, and treatment status. Even though a small upward directional change would be missed with the variable live alone status at the 12-month follow-up, this upward movement is minimal and would be of minor consequence to the overall model of change in psychological distress over time.

Deceased participants. The study excluded those patients who were deceased at the 24-month follow-up as well as those who did not complete follow-up surveys at both 6 months and 12 months. The decision to exclude these patients was made due to the need to have, at minimum, two data collection points in order to form a trajectory for multivariate analyses. Additionally, patients whose only two data collection points were: (1) within four months of diagnosis and (2) at six of diagnosis following diagnosis, were excluded due to the lack of clinically important information that such a brief trajectory could provide. In sum, a total of 42 patients were excluded from study due to non-response, with 27 deceased patients at 24 months and 15 patients with no response to surveys at the 6-month and 24-month follow-ups. Table 2 presents the attrition of deceased AYA participants across the study period. Table 3 shows sociocultural patient characteristics for the current study sample, which was comprised of 173 AYA cancer patients (n=173). The heterogeneous mix of cancer types among this sample is displayed in Table 4.

Respondents and non-respondents. Across the two-year study period, 215 patients responded to the baseline survey, 169 patients responded to the 6-month follow-up survey, and 141 patients responded to the 24-month follow-up survey. Bivariate statistical comparisons using chi-squared tests were used to determine any statistically significant differences between survey respondents and non-respondents in terms of demographic characteristics, live alone status, health status related to readiness for work/school, treatment status, type of treatment received, employment/education status, and severity of psychological distress (Table 5). A greater percentage of AYA patients who responded to both the 6-month and 12-month follow-ups were younger, receiving adjuvant chemotherapy/radiation, and on treatment at the time of the survey. AYA participants had a mean age of 23 years (SD=8.95).

Power analysis.

Power analysis was conducted to determine the power that would be achieved in the current study's hypothesized relationship between occupational status and psychological distress outcomes across time. In other words, given the study sample of 173 AYA participants, it is necessary to determine the probability of finding a statistically significant difference ($p<0.05$) in psychological distress that is measured by the Global Severity Index (GSI) score of the BSI-18.

In order to estimate an effect size for the current study, the researcher searched extant literature for similar studies using the BSI-18 instrument for cancer patients. Such studies were not quite parallel to the current inquiry in terms of research design. Overall, previous studies observed small changes in psychological distress over time within a range of effect sizes. On the larger end, Sherman et al.'s (2008) study (n=94) of changes in psychosocial adjustment among multiple myeloma patients using the BSI-18, a power of 0.84 was sufficient to detect a moderately small effect size of 0.3. In the middle of this range of effect sizes, Carlson et al.'s (2004) investigation of distress and fatigue among adult cancer patients (n=2776) used the BSI-18 distress and found significant effects related to participants' ethnicity, income, type of cancer, and treatment status with a Cohen's d effect size of 0.2. On the smaller end, Schover et al.'s (2006) study of African American breast cancer patients (n=60) found statistical significance in

BSI-18 outcomes (d=0.14). Additionally, Mallinckrodt et al.'s (2012) investigation of distress after breast cancer treatment (n=145) utilized the BSI-18 and found statistical significance with a Cohen's d effect size of 0.11. Based on these findings, an effect size of .25 was used to estimate power given a fixed sample size of 173. An effect of .25 is relatively small, in Cohen's terms, but arguably large enough to be of potential importance.

Figure 5[1] illustrates the relationship between power and effect size given a sample of 173 ($p<0.05$). As shown in Figure 5, the study would have more than adequate statistical power, ($1-\beta=.95$; ES=.25). Note that this power calculation does not account for the effect of specific covariates utilized in this analysis.

Variables and Measures

Descriptive statistics for variables and their measures can be found in Tables 6-8, including baseline frequencies, means, and standard deviations, and where applicable, data at all three time points.

Psychological distress. The study's primary dependent variable is psychological distress. The Brief Symptom Inventory-18 (BSI-18) was used to measure psychological distress. Widely used in oncology care, the BSI-18 is an efficient measure for monitoring patients' psychological symptoms (Derogatis, 2001). Responses to self-reported items assess the extent to which participants have experienced symptoms of psychological distress over the past seven days. In sum, all responses to the BSI-18 produce a Global Severity Index (GSI) as an indication of overall psychological distress; the 18 statements are equally divided to compute scores for three subscales – depression, somatization, and anxiety. The overall GSI score ranges from 0 to 72, with higher scores indicating higher severity of psychological distress, and a suggested cut

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[1] G*Power v.3.1 software (Faul et al., 2013) was utilized to conduct the aforementioned power analysis.

point of 63 indicating significant distress (Derogatis, 2001). For each of the three subscales – depression, somatization, and anxiety – total scores were calculated from Likert scale responses to six items and range from 0-24. Table 8 details BSI-18 GSI and subscale scores for respondents at baseline.

Employment status. Employment status is an independent variable in the study. The baseline questionnaire asked: "What was your employment status JUST BEFORE your cancer diagnosis? and "What was your employment status NOW? Following, questionnaires at each subsequent time point asked: "What was your employment status NOW? Employment status was then measured by participants indicating one of the following responses: Employed full-time, Employed part-time, Full-time homemaker, Full-time student, On temporary medical leave/disability, Unemployed, Permanently unable to work (Table 6).

Although work and school settings present different sets of challenges, they share a common set of possible benefits to AYA cancer patients' mental health outcomes. Therefore, the present research focused on the concept of being occupied, whether that occupational engagement is with work or school. Accordingly, employment status was recoded into the dummy variable occupational status change in the current study.

Occupational status change. Occupational status change was a dependent variable of interest in aims one and two, and a predictor variable of interest in aim three. Occupational status change was a dummy variable created by recoding the employment status variable across the two years of study into two categories: (1) remained in work/school and (2) stopped or remained out of work/school.

Treatment status. The study was interested in treatment status as a covariate specific to AYA cancer patients in examining the relationship of employment/education status to psychological distress. The variable was, therefore, measured by whether participants are on treatment or off treatment (Table 7), as well as the type of treatment they were involved with as follows: in-patent chemotherapy, outpatient chemotherapy, oral chemotherapy, radiation, bone marrow transplantation, surgery.

Health status – fatigue and cognitive function. Health status related to readiness to work were represented in the current study by the two covariates fatigue and cognitive function. Both fatigue and cognitive function were measured by a yes/no responses to corresponding questions in the health status checklist of the participant questionnaire. This checklist of health symptoms was derived by Zebrack and colleagues (2013) to assess self-reported indication of 11 common side effects related to cancer and its treatments over the past month – i.e. shortness of breath; problems with memory, attention, or concentration; frequent or severe stomach pain, pain in your chest (heartburn), or indigestion; ringing in the ears; pain in your joints; weight loss; frequent fevers; lack of sleep or trouble sleeping; frequent tiredness or fatigue; frequent mouth sores that impact eating and drinking; and frequent headaches.

Specifically, the question related to fatigue asks whether problems with frequent tiredness or fatigue have been experienced in the past month whether related to cancer or not. Meanwhile, the question related to cognitive function asks whether problems with memory, attention, or concentration have been experienced in the past month whether related to cancer or not.

Sociocultural patient characteristics. Sociocultural patient characteristics are covariates in the study of the relationship between occupational status change and psychological distress. Sociocultural patient characteristics were measured according to demographic survey responses to the variables age, gender, race/ethnicity, income, live alone status, and geographic location as detailed in Table 3.

Consistent with the literature and prior studies of AYA participants in the Hopelab longitudinal dataset (Zebrack et al., 2013), Tables 1 and 3 display the frequency of age in three categories: 14-17 years, 18-25 years, and 26-39 years (Arnett, 2000; Aubin, 2011). Respectively, these three categories represent adolescence, emerging adulthood, and young adulthood. Although this table displays age according to these three categories, the present research treated age as a continuous variable where possible, as the literature suggests soft limits around the chronological definitions of AYA life stages (Hammond, 2016).

In the present research, race is intentionally dichotomized into two categories: White or Non-White. The dataset used in the present research did not contain sizeable representation of different Non-White racial groups, which limited potential analysis of such intergroup difference. As well, race and ethnicity were not isolated in the HopeLab study's survey instrument (Zebrack et al., 2013). Rather, respondents were asked to identify their race/ethnicity according to the categories: White/Caucasian; Black or African American; Asian/Pacific Islander; Hispanic/Latino; and American Indian/Alaskan Native (Table 3). Consequently, the researcher utilized the opportunity to examine a two-category definition of race/ethnicity that would allow for the examination of differences between White and Non-White AYAs. Table 3 shows the frequency of AYA participants according to racial/ethnic categories used in the current study's survey instrument. Within the current study, White/Caucasian were re-coded as White, with all remaining racial/ethnic categories were recoded as Non-White. Note that the majority of AYA participants in the Non-White group were Hispanic/Latino. Although there may be some White AYA participants among AYA participants who identified as Hispanic/Latino, these individuals were categorized as Non-White in the current study in acknowledgement of their affiliation with an ethnic minority group.

Analysis Plan

In preparation for the study’s longitudinal analyses, preliminary descriptive statistics were run on all study variables using SPSS v.24. Results from preliminary analyses of baseline data are presented in Tables 6-8, alongside corresponding narrative descriptions of variables and measures. Prior to employing longitudinal techniques, data were converted from SPSS v.24 to STATA v.14 format. Stata datasets were then maintained in wide data format for bivariate analyses, and subsequently restructured from wide to long data format for multivariate analyses.

Aim one. Trajectories of psychological distress and its covariates (Figure 6) were described with bivariate statistical comparisons using chi-squared, analysis of variance (ANOVA), and t-tests as appropriate. Data on psychological distress trajectory, treatment status, health status, and sociocultural patient characteristics were collected at three time points: baseline (within 4 months of diagnosis), 6 months, and 24 months following a cancer diagnosis.

The dependent variable in these bivariate analyses was psychological distress as measured by the Brief Symptom Inventory (BSI-18) Global Severity Index (GSI) to indicate overall psychological distress. As well, each of the BSI-18 subscales: depression, somatization, and anxiety, were included to indicate the presence of depression, somatization, and anxiety among AYAs. The covariate treatment status was measured by information collected from clinic records indicating whether the patient is on-treatment or off-treatment as well as the type of treatment they are involved with at the time of the survey as follows: in-patient chemotherapy, outpatient chemotherapy, oral chemotherapy, radiation, bone marrow transplantation, surgery. The covariate health status is represented by symptoms of fatigue and cognitive function as measured by participants’ yes or no responses to corresponding questions within the health status checklist of the questionnaire. The covariate age is measured as a continuous variable to examine the relationship of age on occupational status change across time. The covariate gender is a two-category variable (female; male) that indicated whether being female or male influenced the trajectory of employment/education. The covariate race/ethnicity is another two-category variable (White; Non-White) that indicated whether self-identifying as White or Non-White influences occupational status change. The covariate live alone status is defined according to the five categories of AYAs' living situation in Table 3, thereby investigating the influence of living alone and sharing a household with various members on AYAs' employment/education trajectory. Lastly, geographic location was studied in terms of the hospital site at which the survey was conducted to reveal any regional influence on occupational status change.

The intent of Aim one, Hypothesis one, was to isolate trajectories of psychological distress according to Bonanno's (2004) stress-coping model (Figure 2), which depicts four trajectories of disruption to normal functioning following a traumatic event – chronic, delayed, recovery, and resilient.

Aim two. Linear mixed-effects models were generated to examine the relationship between theoretical trajectories of occupational status and psychological distress across two years after initial cancer diagnosis among adolescent and young adult cancer patients, including examination of treatment status, health status related to readiness to work, and sociocultural factors (Figure 7). Data on occupational status, psychological distress, and their covariates were collected at three time points: baseline (within 4 months of diagnosis), 6 months, and 24 months following a cancer diagnosis.

Consistent with aim one, the dependent variable in linear mixed-effects modeling was psychological distress as measured by the BSI-18 GSI and its subscales. As well, the covariates treatment status, health status, and each of the sociocultural patient characteristics of interest (age, gender, race/ethnicity, live alone status, and geographic location) was captured at three time points. The independent variable employment/education was measured by the distinction of full-time and part-time occupied employment/education status, as well as the dummy variable occupational status change, which was created by recoding the employment status variable across the two years of study into two categories: (1) remained in work/school and (2) stopped or remained out of work/school. Multivariate analyses was run inclusive of these important factors and a linear mixed-effects model of change in psychological distress over time was produced.

Ethical and Cultural Considerations

This study was a secondary analysis of data collected by Dr. Brad Zebrack at the University of Michigan, School of Social Work. As previously detailed in the Data Source section, IRB approval processes, protocols, and procedures for research with human subjects at each participating institution was secured and maintained, including participant consent/assent as appropriate.

Prior to recruitment to the study, participants were provided verbal and written communication on informed consent, the voluntary nature of their participation, confidentiality of all data collected, and any benefits and/or risks to participation. Participants were also informed and reminded throughout the study period that their participation was voluntary, their decision to participate or not will have no influence on their health care, health coverage or have any other consequence, and they should at no time feel coerced into answering questions nor continuing in the study if they wish to drop out. The researcher also made sure participants understood that all of their responses would remain confidential and coded so that all participants remain anonymous. The benefits and risks of participation were fully explained in detail to all study participants.

CHAPTER 4

RESULTS

Introduction

This chapter presents the results of methods utilized by the researcher to investigate how trajectories of employment/education and psychological distress are characterized, and perhaps, associated with each one another, across two years following a cancer diagnosis among socioculturally diverse adolescent and young adult (AYA) patients. First, the researcher begins with descriptive results to define and characterize trajectories of psychological distress for AYA participants in the current study, followed by bivariate results to test hypothesis one, by describing the relationship between treatment status and psychological distress. Second, descriptive results define and characterize trajectories of occupational status for AYA participants in the current study, followed by bivariate results to test hypothesis two, by describing the relationship between trajectories of employment/education and trajectories of psychological distress. Third and finally, the researcher explicates multivariate results that depict change in psychological distress and its covariates, concluding the chapter with a model of change in psychological distress across two years following a cancer diagnosis among a socioculturally diverse sample of AYA cancer patients.

Description of Psychological Distress Trajectories

Psychological Distress Trajectories Defined. In order to categorize the study sample into psychological distress trajectories, the researcher first defined Bonanno's (2004) stress and coping trajectories that were previously introduced in the literature review chapter (p. 32) in relation to the current study. AYA participants' BSI-18 Global Severity Index (GSI) scores were used to indicate psychological distress at each of the four time points within the original

HopeLab dataset (Zebrack et al., 2013): baseline, 6-month follow-up, 12-month follow-up, and 24-month follow-up.

As a diagnostic tool, the BSI-18 measures psychological distress with a GSI score of greater than 63 indicating *caseness* – i.e. significant psychological distress – and a GSI score less than or equal to 63 indicating *no caseness* – i.e. non-significant psychological distress. A dummy variable for caseness of psychological distress was created, and the researcher defined each trajectory of psychological distress according to patterns of *caseness* or *no caseness* at each data collection time point.

Following decision rules used in Kwak et al.'s (2013) prior study of the Hopelab dataset, the *chronic* distress trajectory was defined by patients whose GSI scores indicated caseness for psychological distress across all time points in the study. Table 9 presents the patterns of caseness on GSI scores that created the psychological distress trajectories in the current study. The *delayed* distress trajectory was defined by patients whose GSI scores indicated caseness for psychological distress at 24-month follow-up, regardless of whether they indicated caseness at diagnosis, 6-month, or 12-month follow-ups. The *recovery* distress trajectory was defined by patients whose GSI scores indicated no caseness for psychological distress at 24-month follow-up, regardless of whether they indicated caseness at diagnosis, 6-month, or 12-month follow-ups. Lastly, the *resilient* distress trajectory was defined by patients whose GSI scores did not indicate caseness for psychological distress at any of the data collection time points in the study.

As previously mentioned, mean GSI and subscale scores for all respondents at baseline are shown in Table 8. According to BSI-18 scoring guidelines, non-patient community norms for GSI and subscale scores have a mean of 50 (standard deviation=10). In comparison to non-patient community norms (mean=50, standard deviation=10), AYA participants in the current study sample had elevated mean scores for GSI (mean=57.22, standard deviation=10.09) as well as for all subscales (somatization, depression, anxiety), with a GSI mean score of 59.44 (standard deviation=10.02) for the somatization subscale, which is particularly high relative to non-patient community norms.

Frequencies of AYA participants categorized according to their respective psychological distress trajectories are summarized in Figure 8. The majority of study participants were categorized by the delayed distress trajectory (n=122), whereas the least number of participants (n=8) were on the recovery distress trajectory. Mean GSI scores for each of the four psychological distress trajectories at each of the four data collection time points in the original Hopelab study are also reported in Figure 8. With the exception of those on the resilient distress trajectory, mean scores for AYA participants are higher than non-patient community norms (mean=50, standard deviation=10) across all four time points. Although AYA participants on the resilient distress trajectory were defined by not indicating caseness for psychological distress at any of the three time points, at the 24-month follow-up, the mean GSI score (62) for AYA participants on the resilient distress trajectory was only one point below the cut-point of 63 indicating caseness for psychological distress.

Psychological Distress by Occupational Status Trajectory

In addition to descriptive results, one-way analysis of variance (ANOVA) was conducted to determine whether psychological distress was related to occupational status trajectory, by comparing GSI mean scores for each occupational status trajectory. Significant differences were found only at baseline [F(4, 168)=2.53, $p<0.05$] and 6-month follow-up [F(4, 154)=2.67, $p<0.04$]. However, no significant differences were found at 12-month follow-up [F(4, 145)=2.19, $p<0.08$] and 24-month follow-up [F(4, 132)=1.46, $p<0.22$]. Table 10a shows mean

GSI scores at baseline and 6-month follow-up. Table 10b shows results from ANOVA and subsequent post-hoc comparisons using Bonferroni corrections to determine which occupational status trajectories had significant differences between each other. At both baseline and 6-month follow-up, significant differences in mean GSI scores were found between the extended leave and remained occupied occupational trajectories (Table 10b). More specifically, results indicate that AYA participants on the extended leave trajectory had worse psychological distress outcomes (GSI mean scores) than those on the remained occupied trajectory at both baseline and 6-month follow-up (Table 10b).

Sociocultural Patient Characteristics, Health Status, and Psychological Distress

Bivariate statistical comparisons using chi-squared analyses depicted the relationships between the independent categorical variables (sociocultural patient characteristics, health status, and treatment status) and each psychological distress trajectory (dependent categorical variable) as shown in Tables 11 and 12. The chi-squared test for independence is used to determine whether two categorical variables in a given population are related, and the recommended frequency count for each cell in the analysis should be no less than five (Field, 2009). Additionally, Cramer's V statistics were generated. Cramer's V indicates magnitude of the effect size with small effect=0.1, medium=0.3, and large=0.5 (Field, 2009).

Gender. No statistically significant association ($p<0.09$) was found between female and male AYA participants and their psychological distress trajectories.

Race. Race was a significant factor ($p<0.03$) associated with psychological distress trajectory. The chronic distress trajectory had a greater percentage of AYA participants who were Non-White. Ten percent of Non-White AYA participant were on the chronic distress trajectory, whereas only 1% of all White participants were associated with chronic distress. On the other hand, 24% of White AYA participants were associated with the resilient distress trajectory, compared to only 15% of Non-White participants.

Health Status – Fatigue No statistically significant association ($p<0.23$) was found between self-reported symptoms of fatigue and psychological distress trajectory..

Health Status – Cognitive Function. Cognitive problems were found to be significantly associated with the chronic distress trajectory ($p<0.02$). Nine percent of AYA participants with cognitive problems were on the chronic distress trajectory, whereas only 3% of those without cognitive problems were on the chronic distress trajectory. Additionally, AYA participants with no cognitive problems (27%) were more likely to be on the resilient psychological distress trajectory, compared to those with cognitive problems (11%).

Treatment Status. Bivariate analyses did not generate any statistically significant association ($p<0.86$) between AYA participants' treatment status – whether on treatment or off treatment - with psychological distress trajectories.

Live Alone Status. No statistically significant association ($p<0.63$) was produced regarding the relationship between live alone status and psychological distress trajectory. However, there was limited variation in live alone status among AYA participants. Regardless of psychological distress trajectory, the vast majority of AYA participants in the current study reported not living alone. Across all psychological trajectories, a total of only eight AYA participants indicated living alone.

Geographic Location. No significant correlation ($p<0.39$) was found between AYA participants' hospital location (University of Southern California/Children's Hospital Los Angeles, University of Texas Health Science Center at San Antonio, and Oregon Health and Science University) and psychological distress trajectory.

Treatment Type. In terms of surgical treatment, adjuvant chemotherapy/radiation, or ongoing treatment, no significant association ($p<0.92$) was found between treatment type and psychological distress trajectory. The current study included very few AYA participants who did not receive adjuvant chemotherapy/radiation, only 14 of the total sample of 173 participants (8%). Table 4 displays the frequencies of all cancer types among AYA participants in the present study. Leukemias (24%) and lymphomas (22%) accounted for 46% of the total sample, and these blood cancers among AYAs typically require aggressive intervention with adjuvant chemotherapy and radiation treatments.

Age. The variable age was treated as a continuous variable, with no statistical significance in ANOVA results ($R^2=0.0434$, $p<0.07$) as shown in Table 9. It is important to note that the R-squared value of zero (rounded down from 0.0012) does not necessarily mean there is miniscule correlation between the variables age and psychological distress. Rather, R-squared is an indication of the extent to which the variable age explains variation in the response variable around its mean (Field, 2009), i.e. the mean of psychological distress for the current study. R-squared of 0.0434 means that this correlation explains the relationship between age and psychological distress to a very small extent – i.e. <0%.

Hypothesis One Bivariate Results – Treatment Status

The first hypothesis in the present research predicted that being on treatment would have a positive association with psychological distress across time, controlling for health status, and sociocultural factors. To test hypothesis one, bivariate statistical analyses using independent samples t-tests were conducted to investigate the between group differences of AYA participants who were on cancer treatment compared to those off treatment across time, controlling for health status and sociocultural factors (Table 12). The hypothesized positive association between being on cancer treatment and psychological distress was not supported. No significant associations were found between treatment status and psychological distress at any of the four time points in the Hopelab dataset: baseline (t-statistic=0.20, p<0.42), 6-month follow-up (t-statistic=0.22, p<0.41), 12-month follow-up (t-statistic=-2.99, p<1.00), and 24-month follow-up, (t-statistic=1.15, p<0.13).

Description of Occupational Status Trajectories

Occupational Status Trajectories Defined. Occupational status trajectories for AYA participants in the current study were created according to the theoretical trajectories of occupational status change previously explained in the literature review chapter (p. 17). Based on individuals' engagement or disengagement with work/school at each time point, the researcher categorized AYA participants according to the theoretical trajectories of occupational status change illustrated in Figure 3. Figure 9 illustrates the three trajectories of occupational status change of interest in the current study, which the researcher named: *restart, extended leave, and postponed leave.* The *restart* trajectory was defined by AYA participants who were occupied with work/school before cancer, not occupied at diagnosis, but occupied at the 24-month follow-up. The *extended leave* trajectory was defined by AYA participants who were occupied with work/school before cancer, not occupied at diagnosis and not occupied at the 24-month follow-up. The *postponed leave* trajectory was defined by AYA participants who were occupied with work/school before cancer, occupied at diagnosis, but not occupied at the 24-month follow-up.

The study sample (n=175) was comprised of 64 AYA participants on the restart occupational status trajectory, 22 on the extended leave trajectory, and 35 on the postponed leave trajectory. There were 63(36%) AYA participants who had no change in their occupational status across the observation period. The majority (75%) of these occupationally unchanged AYA participants *remained occupied* with school/work across the two years of observation, while 25% were *unoccupied.* Although the current study's hypothesized interest is focused on change in occupational status, occupational trajectories that exhibited no change in occupational status – i.e. *remained occupied* or *unoccupied* – were included in analysis for a comprehensive representation of occupational engagement within the study sample.

Figure 10 shows trends in psychological distress levels, according to mean GSI scores, for each of the five occupational status trajectories across the two years of study. An overall U-shaped trend was observed across all occupational status trajectories, with the lowest mean GSI scores at 6-month follow-up and the highest at 24-month follow-up. Furthermore, the extended leave trajectory exhibited the highest levels of psychological distress across all three time points, whereas the lowest levels of psychological distress were observed with the remained occupied trajectory. However, in terms of trajectories of occupational status change, AYA participants on the restart occupational trajectory had lower mean GSI scores at diagnosis and six-month follow-up, in comparison to those on the extended leave and postponed leave trajectories.

For each of the five occupational status trajectories – restart, extended leave, postponed leave, remained occupied, and unoccupied – somatization subscale scores are detailed in Figure 11, depression subscale scores are provided in Figure 12, and anxiety subscale scores are listed in Figure 13. AYA participants categorized by the extended leave occupational trajectory demonstrated the highest levels of somatization and depression across all time points. However, AYA participants on all three trajectories of occupational status change – restart, extended leave, and postponed leave – had mean scores exceeding the clinically significant threshold (>63) at the 24-month follow-up for all three BSI-18 subscales: somatization, depression, and anxiety.

Hypothesis Two Bivariate Results – Occupational Status

The second hypothesis in the present research predicted that AYA participants on the restart occupational status trajectory would be associated with decreased psychological distress at the 24-month follow-up, i.e. the resilient distress trajectory. To test hypothesis two, both bivariate and multivariate analyses were conducted. Results from bivariate analyses using chi-squared tests are reported in Table 13. Significant correlation ($p<0.01$) was found between occupational status trajectory and psychological distress trajectory. AYA participants who were on the extended leave occupational trajectory (14%) or were unoccupied (13%) were most likely to be on the chronic distress trajectory; whereas, those on the restart (80%) and postponed leave (84%) occupational trajectories were most likely to be on the delayed distress trajectory. Contrary to the hypothesized relationship, bivariate analyses did not show that AYA participants on the restart occupational status trajectory were more likely to be on the resilient distress trajectory.

Modeling Change in Psychological Distress over Time

Linear mixed-effects modeling was done to examine change in psychological distress and its correlates over time, including further evaluation of occupational status trajectories. Repeated measures of psychological distress (GSI scores) at each of the three time points (diagnosis, six-month follow-up, and 24-month follow-up) were considered nested within individual AYA participants in the present study. Four linear mixed-effects models were generated with user-determined introduction of different categories of predictor variables in order to would reveal incremental changes in the model with the addition of different types of covariates. Results from the four linear mixed-effects models are reported in Table 14.

The first linear mixed-effects model included only the main effects of time invariant occupational status trajectories and psychological distress over time (Table 14). All five occupational status trajectories were included, and psychological distress outcomes were measured with GSI scores. Model 1 is a significant model (Wald X^2=14.59, p<0.01). Results from Model 1 show that AYA participants on the extended leave occupational status trajectory were significantly more likely to have increased psychological distress (p<0.01) with a parameter estimate of 6.21 higher than the remained occupied trajectory for every unit increase (Table 14).

Results from the second linear mixed-effects model are also shown in Table 14. Model 2 was a significant model (Estimate=5.65, p<0.01); it included the main effects and all the time-invariant covariates: age, gender, race, and geographic location. Specifically, Model 2 generated significant findings with the extended leave (Estimate=5.65, p<0.01) and postponed leave (Estimate=4.66, p<0.04) occupational trajectories being positively associated with psychological distress. No significant random effects were found in Model 2 for the time-invariant variables age, gender, race and geographic location.

The third linear mixed-effects model included the main effects and all of the aforementioned time-invariant as well as time-variant variables and their interactions with the time point (Table 14). Model 3 is a significant model (Wald X^2=280.74, p<0.01). Model 3 yielded statistically significant associations for the variables occupational trajectory, gender, race, treatment status and health status. More specifically, a statistically significant association was observed between being male (Estimate=1.11, p<0.03) and Non-White (Estimate=3.73, p<0.01) and increased psychological distress. Simultaneously, statistically significant inverse correlations with psychological distress were found among AYA participants who were on treatment (Estimate= -1.92, $p<0.03$) as well as those having symptoms of fatigue (Estimate= -3.69, $p<0.01$).

Finally, in order to generate the most parsimonious fourth and final linear mixed-effects model, the researcher eliminated interactions with non-significant estimates for their respective random effects. This fourth model depicts the main effects of occupational status trajectories and psychological distress and its covariates (age, gender, race, geographic location, live alone status, treatment status, fatigue, and cognitive function) across two years following a cancer diagnosis among the study sample of socioculturally diverse AYA cancer patients (Table 14). Model 4 is a significant model (Wald X^2=220.81, $p<0.01$). Model 4 resulted in significant effects with the extended leave occupational trajectory (Estimate=3.47, $p<0.05$), treatment status (Estimate=-2.45, $p<0.01$), and fatigue (Estimate=-3.51, $p<0.01$).[2]

For each of the four linear mixed models, Akaike's information criterion (AIC) and Bayesian information criterion (BIC) scores were calculated to compare the goodness-of-fit of each model. Both AIC and BIC are relative values commonly used to assist in model selection, with a lower score indicating higher quality and a better model fit given a particular dataset (Fan & Lee, 2012). According to Hedeker and Gibbons (2006), although both AIC and BIC fit statistics are useful, AIC criterion has greater relevance for variance-covariance structures such as those modeled in the present study. Table 14 displays the resulting AIC and BIC scores for each model. Based on both AIC and BIC scores, Model 2 is an improvement on Model 1 and Model 3 is an improvement on Model 2. However, Model 4 has higher AIC and BIC scores than Model 3, and is therefore, not an improvement on Model 3. In short, Model 3 is the best fitting model, with the lowest AIC and BIC scores relative to the other three models. Model 3 included

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[2] Table 15 displays results from two additional linear mixed models (Model 5 and Model 6) that respectively depict the effects of dropped health status covariates and added 12-month data.

the main effects, all time-invariant variables, as well as all time-variant variables and their interactions with time point.

Hypothesis One Multivariate Results – Treatment Status

Contrary to bivariate findings, multivariate analyses resulted in statistically significant findings for the variable treatment status. Table 14 shows that being on treatment was associated with decreased psychological distress across time in Model 3 (Estimate=-2.34, p<0.01) and Model 4 (Estimate=-2.49, p<0.01), with Model 3 being the better fitting model. Hypothesis one is not supported, predicting that being on-treatment has a positive association with psychological distress across time, controlling for health status and sociocultural factors. On the contrary, a negative association between being on treatment and psychological distress was shown.

Hypothesis Two Multivariate Results – Occupational Status

In terms of hypothesis two, multivariate analyses did not show a significant relationship between AYA participants on the restart occupational trajectory and psychological distress across time. Although a significant positive relationship between the extended leave occupational trajectory and psychological distress was observed across Models 1, 2, and 4, this significance is not found in the best fitting Model 3. Hypothesis two, predicting that AYA participants on the restart occupational status trajectory would be associated with decreased psychological distress at the 24-month follow-up, is not supported.

Table 15 shows results of two additional models (Model 5 and 6) generated for post-hoc comparison. Model 3 is the best fitting model from Table 14, and is shown in Table 15 for ease of reference. Model 5 includes all the same three time points and variables as Model 3, with the exception that it excludes the health status covariates (fatigue and cognitive dysfunction). Model 5 is a significant model (Estimate=36.25, p<0.01); however, the significant finding with the fatigue variable drops out if the health status covariates are not included. Model 6 also excludes health status covariates, but includes data from all four time points: baseline, 6-, 12-, and 24-month follow-up. Model 6 is a significant model (Estimate= 35.81, p<0.01); however, significant findings with the fatigue and race variables drop out if 12-month data is included. AIC and BIC comparative fit statistics were generated to determine the best fitting model. When comparing Models 1-5, Model 3 has the lowest AIC and BIC fit index scores and is therefore the best fitting model.

CHAPTER 5

DISCUSSION

Introduction

One of the great successes in adolescent and young adult (AYA) oncology is the dramatic improvement in cancer survivorship for this age-defined population, with the majority of today's younger cancer patients able to return to occupational roles. There is a growing cohort of 600,000 AYA cancer patients (ACS, 2016b), whose life expectancy may extend well into older adulthood, but for whom the adverse long-term effects of cancer treatments and their influence on employment outcomes remains to be understood (de Boer et al., 2009). In response, the present research provided new insights into changes in employment/education status and psychological distress over a two-year period of observation by capturing a host of relevant factors among a socioculturally diverse sample of AYA cancer patients from the Hopelab longitudinal dataset (Zebrack et al., 2013).

First, the researcher depicted theoretical trajectories of psychological distress following a cancer diagnosis and its key factors; specifically, testing the relationship between treatment status and psychological distress trajectory. Second, the relationship between theoretical trajectories of occupational status change following a cancer diagnosis and theoretical trajectories of psychological distress were identified and investigated, testing a hypothesized relationship between two of the trajectories. Third and finally, the relationship between the aforementioned occupational status trajectories and psychological distress levels were modeled, thereby deriving a multivariate model of change in psychological distress over time among socioculturally diverse AYA cancer patients.

The Hopelab longitudinal dataset is comprised of AYA cancer patients ages 14-39 years and includes clinical data on participants' socio-demographics as well as AYA participants' self-reported responses to surveys across a number of biopsychosocial domains related to occupational engagement including assessment of psychological distress at each of the data collection time points (Zebrack et al., 2013). Distinguished by its inclusion of a broad scope of psychosocial measures targeted at a diverse population of AYA patients, the Hopelab dataset was collected by Zebrack et al. (2013) across a two-year period, from pediatric and adult cancer care centers in three metropolitan areas: Los Angeles, Portland, and San Antonio. Since the present research is concerned with change in psychological distress across time that is inclusive of the multifaceted sociocultural diversity of AYA cancer patients, the sample of young cancer patients within the HopeLab longitudinal dataset was particularly appropriate.

Change in Psychological Distress Over Time

The overall trend in psychological distress among AYA cancer patients across the two years of observation in the current study formed a U-shaped curve that bottoms out at the 6-month time point, then climbs to the 24-month time point. In other words, psychological distress was heightened at diagnosis, then declined until six months after diagnosis showing improvement. Thereafter, psychological distress climbed upward between the 6- and 24-month follow-ups indicating that psychological distress among AYA participants persisted and worsened during that period. On average, psychological distress at 24-months following diagnosis was worse than at baseline for the current study sample. Evidence that AYAs experience psychological distress at clinically significant levels for as long as two years following initial cancer diagnosis points to enduring needs.

Although criteria for psychological caseness were technically met by AYAs on the resilient distress trajectory, AYA participants in the current study met this criteria with a close margin at 24-month follow-up. More specifically, a GSI score indicating no caseness for psychological distress across all time points was required to be categorized on the resilient distress trajectory. However, the mean GSI score for those on the resilient distress trajectory in the current study was 62 at 24-month follow-up, just one point below the cut-point of >63 for caseness indicating distress. In terms of clinical interpretation, a reasonable argument could be made for these AYAs on the resilient distress trajectory to be described as experiencing delayed distress.

Furthermore, the majority of AYA participants (71%) in the current study were categorized by the delayed distress trajectory (n=122). This finding suggests that symptoms of psychological distress may not reported by AYA patients until as late as 12 months following the initial cancer diagnosis. Ongoing psychological assessments are needed to monitor for the appearance of clinically significant distress.

Moreover, the current study found that AYA participants on the remained occupied trajectory had better psychological distress outcomes (GSI mean scores) than those on the extended leave trajectory at both baseline and 6-month follow-up. This finding is consistent with extant literature on the positive influence of continued participation in work/school roles among cancer patients, and raises more questions. For example, to what extend did AYA participants who remained occupied throughout the two-year observation period have better mental health outcomes as a result of their occupational engagement or as a result of being psychologically stronger than their counterparts on the extended leave trajectory before a cancer diagnosis?

Sociocultural Factors Associated with Psychological Distress

In comparison to non-patient community norms for the BSI-18, the sample of AYA cancer patients in the present research had elevated mean scores for psychological distress, indicating overall worse mental health among AYA cancer patients compared to their non-patient counterparts. This finding is consistent with growing empirical evidence that shows substantially higher rates of psychological disorders in AYAs with cancer when compared with their non-patient peers. Prior study has also shown that AYA cancer patients experience heightened psychological distress compared to older adult cancer patients.

The present research found significant associations between AYA participants' gender, race, treatment status, fatigue, and cognitive function and psychological distress over the two-year period.

Gender. Young men and young women are affected by cancer differently. In the current study, linear mixed-modeling showed a significant positive association between being male and worse psychological distress across two years following a cancer diagnosis. Additionally, gender yielded a significant association with psychological distress trajectory, with a male AYA participants being more likely to experience delayed distress, and female AYAs more likely to experience resilient distress. Specifically, males were more likely to be on the delayed distress trajectory (77%), compared to females (63%). Meanwhile, females were more likely to be on the resilient distress trajectory (27%), compared to males (12%). Previously, Zebrack and colleagues (2013) reported that male AYA cancer patients were less likely to make use of mental health counseling services than their female counterparts. Taken together, these findings are consistent with mounting evidence that teenaged boys and young men facing cancer are at risk for both greater and unaddressed mental health needs.

When gender differences in mental health outcomes are considered for the general population, adolescence is known to be a critical period in which depression rates rise dramatically for both females and males (Hankin & Abramson, 2001). Furthermore, there is an increased risk for depression among females, compared to males, that persists into young adulthood (Hankin & Abramson, 2001). The present research, however, found that being male was associated with worse psychological distress among AYA cancer patients. There is limited knowledge related to the mechanisms of the onset of depressive symptoms among AYAs in the general population, not to mention AYA cancer patients. The current study found that the majority of AYA participants experienced delayed distress. For these AYA cancer participants, psychological distress may not be detected at diagnosis, but heightened levels of distress at clinically significant levels were found later.

Some understanding about the influence of male gender on delays in the expression of psychological distress may be gained by considering the societal burdens of the masculine stereotype. Masculinity has long been associated with physical prowess and virility, and along those lines, popular mainstream stereotypes of cancer survivors are rife with militant imagery and metaphor – e.g. *cancer survivor, thriver, fighter, etc.* – all terminology that may place unnecessary pressure and undeserved blame on the patient who rightfully feels fragile and obliterated. It could, therefore, be argued that gendered expectations of male AYA cancer patients encourages *hypermasculinity,* the "exaggerated exhibition of physical strength and personal aggression" in response to a gender threat (Harris, 2000). Cancer is a gender threat for both young men and women, but societal stereotypes of what it means to be a man are more heavily based in being physically strong to the greater detriment of young men and adolescent boys living with the devastation of cancer on their bodies. That societal emphasis on "staying strong" despite cancer may contribute to delays in the onset of psychological distress among male AYAs is worthy of consideration.

Race. The present study dichotomized race into White and Non-White from a psychosocial and non-biologic orientation for the purpose of examining whether there was any association between the presence or absence of white privilege and psychological distress among AYA cancer patients. As previously described in the literature review chapter (p.30), white privilege refers to the benefits of White racial identity that places such individuals at an advantage (McIntosh, 1988); and empirical study of the intersection of white privilege and health outcomes is limited (Kwate & Goodman, 2014). Consonant with existing literature, the current study found a significant association between being Non-White and worse psychological distress across two years, as well as Non-White (10%) AYA participants being more likely to experience chronic distress compared to their White (1%) counterparts.

That White AYA cancer patients are less likely to experience worse psychological outcomes compared to Non-White patients is not surprising and is consistent with the preponderance of findings in well-established literature pointing to overall poor mental health outcomes among racial minority cancer patients. For example, Durani & Go’s (2016) study of racial and ethnic disparities in survival outcomes among AYA cancer patients with acute myeloid leukemia (AML) found that while Black AYAs had a significantly worse overall survival than Whites. Additionally, overall survival from AML improved over time among White AYAs only. In another study of unequal outcomes, Kahn and colleagues’ (2016) investigation of racial disparities in cancer survival among children and AYAs revealed that although survival from select leukemias and lymphomas among children and AYAs has improved over the past four decades, racial/ethnic differences persist between Black, White, and Hispanic children and AYAs. Specifically with regards to acute lymphoblastic leukemia (ALL), trends demonstrated a convergence of survival rates for white and black pediatric patients with ALL with survival disparities nearly eliminated; however, a divergence in survival rates was still shown for AYA patients (Kahn et al., 2016). Racial disparities remain among AYA patients.

For the most part, the health services literature discusses the added burden experienced by Non-White patients in terms of individuals' level of acculturation to the dominant American mainstream culture and the challenges that less acculturated individuals face in accessing quality health care. What is less documented is the influence of prejudice and discrimination experienced by Non-White patients that may be a contributing factor. In a 2009 large scale study (n=404,277) of health providers' implicit and explicit attitudes about race, Sabin and colleagues found that the strength of implicit bias exceeded self-report among White, Hispanic, and Asian MDs, but not among African American MDs. There is, however, a growing body of evidence suggesting that such implicit biases may result in health disparities related to patient care in the areas of pain management (Goyal et al., 2015; Hirsh et al., 2015; Shavers et al., 2010; Green et al., 2003), access to clinical trials (DeSantis et al., 2016; Eggly et al., 2015; Langford et al., 2014), and end-of-life care (Abdollah, 2015; Smith et al., 2008).

Even less visible in the literature are the privileges related to improved outcomes that White patients experience within health systems compared to their Non-White counterparts. Within the context of cancer care systems that are a subset of larger society, it is essential to consider the influence of *White fragility,* defined as White people's protection from race-based stress (DiAngelo, 2011). In other words, dominant hegemony in our society has designed a culture in which White individuals are protected from the discomfort of race-based stress, even acknowledging the oppression of Non-White individuals. For example, in a dyadic exchange between a White individual and a Non-White individual, White fragility may surface when even a minimum amount of racial stress becomes intolerable, triggering a common scenario in which the White individual uses a range of defensive moves and the Non-White individual (who may be the victim) reassures the White person that s/he is well-intentioned (DiAngelo, 2011). Relating this theoretical explanation to AYA cancer patients, we might examine whether complaints of race-based discrimination from Non-White AYA cancer patients are adequately addressed or dismissed in the interest of protecting the fragility of White clinicians and/or re-instating White racial equilibrium.

If we are to come to greater understanding of how and why some populations of AYA cancer patients do well while others do not, we must examine not only the correlates of failure, but also the correlates of success. On the other side of inquiry into why Non-White AYA cancer patients are experiencing worse mental health outcomes is inquiry into why White AYA cancer patients are experiencing better outcomes. In order to advance progress in health care, it is important to elucidate the benefits associated with White racial identity in our health systems as well as Non-White, rather than following the widespread tradition of focusing solely on negative outcomes among Non-White patient care populations.

Treatment Status and Psychological Distress

Multivariate analyses yielded a significant inverse relationship between being on treatment and psychological distress, indicating that being on treatment is associated with decreased psychological distress. Although this finding counters the hypothesized positive correlation between being on treatment and psychological distress, it complements the overall trend in psychological distress among AYAs that was observed in the current study. Clinically significant psychological distress was observed among AYA participants at diagnosis, but even higher levels of distress were observed at 12 and 24 months following cancer diagnosis.

The majority of AYA participants in the current study were on cancer treatment at baseline (within four months of diagnosis), when psychological distress was elevated to clinically significant levels. At 12- and 24-month follow-up, most AYA participants were no longer on treatment. Despite being off treatment, psychological distress scores among AYA participants rose to clinically significant levels at 12 and 24 months following cancer diagnosis. What's more, the majority of AYA participants in the current study were on the delayed psychological distress trajectory, which is characterized by delayed onset of clinically significant distress levels.

Although the impact of cancer treatment varies according to type of treatment and the individual's concurrent health status, the added symptom burden (nausea, pain, sleep disturbances) experienced during treatment can influence an individual's mental well-being by inducing anxiety and depression and influencing their self-perceptions about their ability to return to their occupation (Neary, 2009). With this in mind, the observation of much higher levels of psychological distress in AYA participants at 12 and 24 months following a cancer diagnosis is understandable. Cancer treatment triggers a set of symptoms and side-effects on AYA patients, but as initial symptoms and side-effects dissipate, they are supplanted by another set of health and mental health risks. Not to mention, being a cancer patient navigating a treatment regime can be more demanding than any full-time occupation. It makes sense that as the tasks of being a patient lessen, emotions that previously had no room to surface may then emerge and prompt psychological distress.

Health Status Related to Readiness for Work/School

The AYA development period is a time during which society assumes individuals are in their physical and mental prime, with superhero capacity to take on multiple work/school responsibilities that are innovative and creative, while still having enough energy to engage in rigorous physical exercise and intellectual competition. It can be challenging to contend with sudden declines in physical/mental functioning and possible permanent disability at a time when most feel invincible. For example, it is a slight on a young ego to rely on the assistance of medical equipment (e.g. canes, walkers, oxygen tanks, etc.) and rehabilitation programs designed for frail elderly patients.

There is abundant empirical knowledge affirming that long-term problems with fatigue and cognitive function are widespread barriers that obstruct cancer patients' reintegration into school and return to work. It is also known that AYA cancer patients report higher symptom burdens compared with older adults with the same cancer type (Park & Rosenstein, 2016). Therefore, the present research examined fatigue and cognitive function as variables representing health status related to readiness for work/school.

In bivariate analyses, the current study reported that problems with fatigue and cognitive function were each significantly associated with AYAs' psychological distress trajectory. Specifically, 30% of AYA participants with symptoms of fatigue were on the chronic distress trajectory compared to only 11% of those who did experience fatigue. Additionally, 33% of AYA participants who had cognitive problems were on the chronic distress trajectory, compared to a smaller 12% of AYAs who did not have cognitive problems. However, multivariate results in the present research revealed an inverse relationship between fatigue and psychological distress, demonstrating that AYA participants who reported symptoms of fatigue were significantly associated with lower psychological distress scores.

Fatigue is commonly referred to as one of the most debilitating and enduring symptoms that can be induced by cancer treatment (Neary, 2009). Although knowledge on the mechanism of cancer-related fatigue is not thoroughly understood, the experience of fatigue among cancer patients has been found to be profound, pervasive, and enduring in its impact on the occupational experiences of AYAs. Beringher and colleagues (2016) showed that fatigue in AYA cancer patients with Hodgkin's lymphoma was significantly associated with worse employment and financial outcomes for up to nine years after initial diagnosis. Furthermore, Poort et al. (2017) found that the presence of severe fatigue was associated with a negative impact on quality of life among AYA cancer patients, stressing the importance of detection and management of these symptoms.

The current study expands upon existing evidence by presenting multivariate results that demonstrate an inverse relationship between fatigue and psychological distress among AYA cancer patients within the first two years following a cancer diagnosis. Fatigue has been named as a presenting symptom in criteria for psychological depression and anxiety disorders among the general population, (Fava et al., 2014; Shahid et al., 2016). Whether the experience of cancer-related fatigue differs from that of the general population remains a contested area of clinical interest (Bennett et al., 2004; Drabe et al., 2016; Reinertsen et al., 2017; Spelten et al., 2003). The negative correlation found in the present research further underscores the complex mechanism of fatigue and suggests that covarying factors may attenuate the negative influence of fatigue on psychological distress.

Due to the possible shame and frustration of sudden cognitive impairment, cognitive dysfunction among AYA cancer patients can remain undetected until the problem is quite serious. There is limited evidence related to the workings of cognitive dysfunction and "chemo brain" that is tailored to the AYA cancer patients. However, a large body of evidence in the neuroscience literature demonstrates that the adolescent brain does not reach maturation until the age of 25 years (Johnson, 2009). Empirical evidence on neurotoxicity from cranial irradiation and its association with cognitive dysfunction and decreased IQ scores among childhood cancer patients, has long been established (Meadows et al., 1981). Since brain growth continues well beyond puberty, the full impact of cancer treatments concurrent with AYAs' critical period of brain maturation is yet to be known. Moreover, chronic exposure to stress hormones during adolescence and young adulthood has been shown to affect brain structures involved with cognition and mental health (Lupien et al., 2009). Therefore, it follows that the present research found a correlation between cognitive dysfunction and psychological distress trajectory in bivariate analyses.

Occupational Status Trajectory and Psychological Distress

In three of four linear mixed models (Table 14), statistical analyses involving five theoretical trajectories of occupational status (restart, extended leave, postponed leave, remained occupied, and unoccupied) and psychological distress levels yielded a significant association between being on the extended leave occupational status trajectory and increased psychological distress. This significant result points to heightened psychological distress among those taking extended leave from occupational engagement compared to those on the restart trajectory and postponed leave trajectory. Individuals may take extended leave from work or school due to greater severity of illness and intensive treatment interventions, which would explain why this main effect was attenuated by the addition of timepoint interactions in Model 3 (Table 14).

Stepanikova et al.'s (2017) qualitative study of 50 cancer patients who received hematopoietic stem cell transplantation within the last 2-22 years detailed challenges in the career and financial domains including job insecurity, discrimination due to cancer status/history, career derailment, lack of career direction, delayed goals, financial losses, insurance difficulties, constraints on job mobility, and physical/mental limitations. Furthermore, cancer patients named external factors that alleviated these career and financial challenges – specifically, good health insurance that adequately covered health costs without problems, favorable job characteristics such as low stress, job accommodations such as flexible schedules, and financial buffers such as personal or family wealth (Stepanikova et al., 2017).

Previous findings using the SF-36 Health Survey within the Hopelab dataset (Zebrack et al., 2013) showed that not being involved with work or school was associated with decreased mental health-related quality of life (Husson et al., 2017). However, the current study found no significant association between any of the theoretical trajectories of occupational status and change in psychological distress levels as indicated by the BSI-18 across the two-year period of observation. The BSI-18 is a highly sensitive self-report inventory specifically designed to screen for psychological distress and psychiatric disorders, while the SF-36 Health Survey measures quality of life across eight domains that includes physical- and mental-component summary scores. The current inquiry builds upon Kwak et al.'s (2013) and Husson et al.'s (2017) findings in its identification and examination of trajectories of occupational status change following a cancer diagnosis.

The absence of significant observation related to the restart and postponed leave trajectories of occupational status change may be due to a need for a longer observation period that would allow for further refinement of the definitions of each trajectory. For example, in a study with a five-year observation period, those currently defined as being on the extended leave trajectory may be re-categorized as being on the restart trajectory if they returned to work/school at three years following a cancer diagnosis. Within the current two-year observation period, it's more challenging to determine whether reintegration into work/school was an enduring transition or a temporary stay.

Methodological Limitations

Study Design. Limitations in the study design include the possibility of response bias and non-response bias in the surveys and selection bias in study recruitment. Response bias may be a concern due to questions of validity related to self-reported data. As is the case with many health surveys that pose personal questions, non-response bias may threaten data if non-respondents to the survey would have answered differently from those who did participate.

In terms of selection bias, in recruiting participants to the original Hopelab study sample (n=215) (Zebrack et al., 2013), AYA participants were excluded if the patient or a physician indicated that they were too sick to participate. Those who did not participate, may have been prevented from doing so by their physician. Additionally, those who chose not to participate may have felt they had experiences that they would rather not share, whether they perceive these experiences as being too traumatic. At the same time, those who agreed to participate may have been enthusiastic about volunteering for the study and eager to share their experiences or motivated by physician's influence. Although participant confidentiality was communicated to all potential respondents, some may have still been unconvinced and elected to participate or refrain from participation accordingly. Lastly, a decision was made to exclude deceased patients from the study. This decision could bias results, if all deceased participants were described by a shared covariate that points to a systematic difference among those who died.

Data. The low number of AYA participants on the recovery psychological distress {trajectory (n=8) limits the extent to which findings for these individuals in the current analyses may be generalized. Additionally, there was limited variation in live alone status among AYA participants. Regardless of psychological distress trajectory, the vast majority of AYA participants in the current study reported not living alone. Across all psychological trajectories, a total of only eight AYA participants indicated living alone.

As previously mentioned (p. 41), one data collection time point (12-month follow-up) was removed from to create the study sample (n=175) in the present study. Due to the non-random nature of this missing data for health status variables of interest and after consideration of trends in key variables across all four data collection points, the 12-month time point was excluded. The three time points included in the study were baseline, 6-month follow-up, and 24-month follow-up.

Finally, since this study involved secondary analysis of an existing dataset, some factors relevant to trajectories of employment/education status change among AYA cancer patients were not captured. More specifically, it would have been ideal to include factors such as AYA participants' financial status/wealth, health insurance status, the type of work/school roles they were stopping and engaging in, and their reasons for occupational status changes. Self-reported household income data collected from AYA participants may be unreliable for some younger AYA who may not have provide accurate information due to lack of knowledge.

Implications

Findings from the present research have several potential implications for psychosocial oncology and clinicians who treat and care for AYA patients. Since AYAs must secure a quality of life that they deem worthwhile in order to successfully rally through long periods of rigorous cancer treatments (Butow, 2010), clinicians should provide additional support to help these young patients navigate host of challenges that cancer brings to school participation (Helms et al., 2014), as well as career and financial domains (Stepanikova et al., 2017). For example, to address the unique biomedical and psychosocial needs of younger AYAs and provide motivation through treatment periods, cancer care centers should promote efforts such as Teen Cancer America's AYA-focused hospital units and programs that help young patient to maintain a sense of normalcy and connection to age-appropriate activities and fun amidst the disquieting tumult of life-threatening illness and intervention.

In response to the significant association between Non-White AYA participants and increased psychological distress, the oncology community should respond to ever-mounting evidence that being Non-White is in itself a risk factor. Future research should more closely examine sub-groups within the broad Non-White category to reveal unique factors experienced by racial/ethnic minority AYAs as they engage or disengage with occupational roles following a cancer diagnosis. In doing so, clinicians would attune themselves to the mental health of Non-White patients through a practice of *cultural humility* in health care settings in an effort to redress power imbalances in the patient-physician relationship (Tervalon & Murray-Garcia, 1998). Cultural humility is a lifelong commitment made by clinicians to engage in self-evaluation and self-critique towards developing mutually beneficial and non-paternalistic clinical care in partnership with patients and their communities.

With regard to long-term problems related to fatigue and cognitive function, the growing oncology trend towards providing patients with cancer survivorship care plans holds much promise. Survivorship care plans (SCPs) provide off-treatment cancer patients with treatment summaries and follow-up care plans related to patients' individual diagnoses, treatment history, and anticipated side-, late-, and long-terms effects (Barthel et al., 2016). This is particularly important for AYA cancer patients, who are more likely to live long enough to be affected by some of these risks compared to their older counterparts. Comprehensive assessment of cancer-related fatigue and cognitive dysfunction should be incorporated into survivorship care plans for routine monitoring of health indicators that are associated with psychological distress.

Along with the assessment of fatigue and cognitive function, cancer care providers should suggest practical tips and realistic accommodations that can be made in work/school settings to support the participation of AYA cancer patients in beneficial education/employment roles. For example, tips on helping teachers to appropriately educate students about the impact of their classmate's cancer could help to reduce bullying and discomfort and promote healthy adjustment of AYA cancer patients in the classroom.

The reality is that some AYA cancer patients must work due to financial pressures, even though their jobs are unfulfilling and their participation is obviously exacerbating negative physical and mental health symptoms. Equipping AYA cancer patients with non-stigmatizing strategies to manage cancer-related fatigue and cognitive issues could prevent negative consequences in the work place. For example, suggesting frequent and brief powernaps and short walks to cope with fatigue, or a quieter workspace to improve concentration.

Conclusion

Occupied with cancer, a sizeable growing cohort of adolescents and young adults are surviving the biological threat of cancer on their lives, and dealing with issues of returning to work and school as they adapt to life after a cancer diagnosis and its sequelae. Many AYA cancer patients caught in this quandary have traded one set of risks for another – either die from cancer or live forever changed. Owing to advancements in oncology, cancer survivorship has become a chronic health and psychosocial condition for many AYA cancer patients, who have yet to realize their talents at work and school when cancer hits.

Long after the physical torment of invasive interventions to treat the initial cancer diagnosis, the impact of physical symptoms, psychological distress, and disruption to work/school persists for many AYA patients. Although the mental health benefits of work are well documented, there is limited scientific knowledge on whether and how this relationship applies to AYA cancer patients and their engagement with school and work roles.

The present dissertation research contributed insights to the existing psychosocial oncology literature on adolescent and young adult patients. Empirical evidence in the current study elucidated possible pros and cons in the relationship between trajectories of employment/education and psychological distress across long-term survivorship. To the best of the researcher's knowledge, no study to date has examined the relationship between trajectories of employment/education and psychological distress among a socioculturally diverse group of AYA cancer patients for a period as long as two years.

Future Research

Future research should investigate ways to support patients who must maintain education/employment roles following a cancer diagnosis with more specificity related to various occupational and sociocultural contexts such as: financial status/wealth, health insurance status, types of occupation, reasons for occupational status change, informal support, race/ethnicity, and patient experiences of minority stress.

Cross-Sectional Study. Closer examination of racial and ethnic disparities among AYA cancer patients, beyond the dichotomized categories of White/Non-White in the current study, is warranted and necessary. A valuable contribution would be a cross-sectional study that investigates occupational status change and minority stress among AYA cancer patients at more than five years following diagnosis. Such a study would include a participant sample comprised of a diversity of races/ethnicities, and include a variety of related factors such as financial status/wealth, health insurance status, types of occupation, reasons for occupational status change, informal support, to generate new knowledge on minority stress processes experienced by AYA cancer patients.

Ilan Meyer's (2003) Minority Stress Model is helpful in understanding the association between a variety of minority social statuses and psychological outcomes. Meyer's (2003) theorization distinguishes exposure to excess stress experienced by individuals or groups with minority position, such as Non-White AYA cancer patients, who are the target of prejudice and stigma. Additionally, minority individuals are likely to experience alienation from dominant social structures, norms, and institutions that typically do not reflect the minority culture. Furthermore, AYAs of sociocultural minority status may be still-forming or newly-confirming multiple roles that reflect their affiliations with cultural identity groups (race, ethnicity, gender, sexual orientation, religion), historical experiences (patient experiences, understanding of their place in society, sense of home), as well as the institutional/environmental settings (school, work, hospitals, clinics, online presence) in which they access health care and adjust to being a cancer patient.

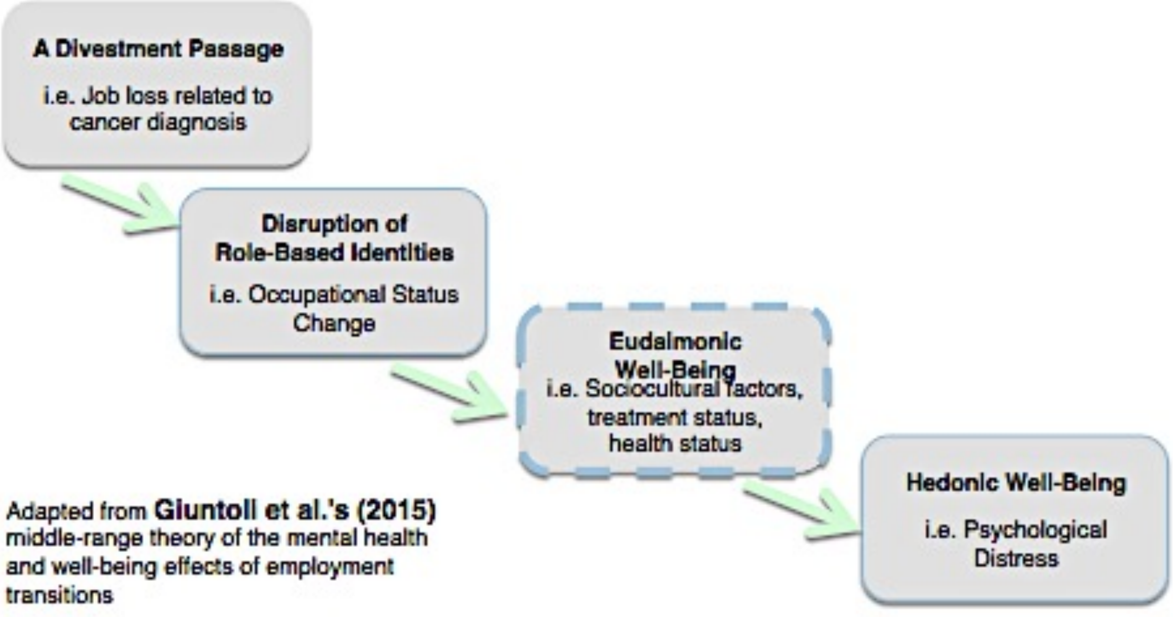
Intervention Development Study. Additionally, an intervention development study should be pursued to examine socially and culturally relevant practical support for AYA cancer patients in various work/school settings, in particular, responding to the needs of AYAs who must return to their occupation while managing cancer treatment, fatigue, and/or cognitive challenges. The current cohort of adolescents and young adults must manage the financial burden of cancer survivorship within already precarious labor markets that offer the young workforce low-wage jobs that are often unstable and lacking nonwage benefits that are essential to sustaining health after cancer. Investigation aimed at deriving knowledge useful to the development of practical resources and support to alleviate these burdens among AYA cancer patients is needed.

Although the current group of increasingly socioculturally diverse AYAs may be comfortable with greater ambiguity in career direction than their predecessors, achieving financial independence remains central to AYAs' sense of having personally reached adulthood (Hammond, 2016). Participation in desired employment and continued attainment of education goals does much more than just maintain social connection with peers and a sense of normalcy amidst the disruption of cancer for AYAs. Occupational engagement has implications for AYAs' future employability, financial outcomes, self-esteem, self-concept, and adult developmental. Deeper investigation into the correlates of occupational engagement among AYAs can help provide young cancer patients with the necessary supports to optimize their participation in employment/education roles and potential for positive contribution to society into the future.

Appendix A

FIGURES

Figure 1. Theoretical Model of Employment Transitions and Mental Health



Adapted from Giuntoli et al.'s (2015) middle-range theory of the mental health and well-being effects of employment transitions

Figure 2. Theoretical Trajectories of Occupational Status for AYA Cancer Patients

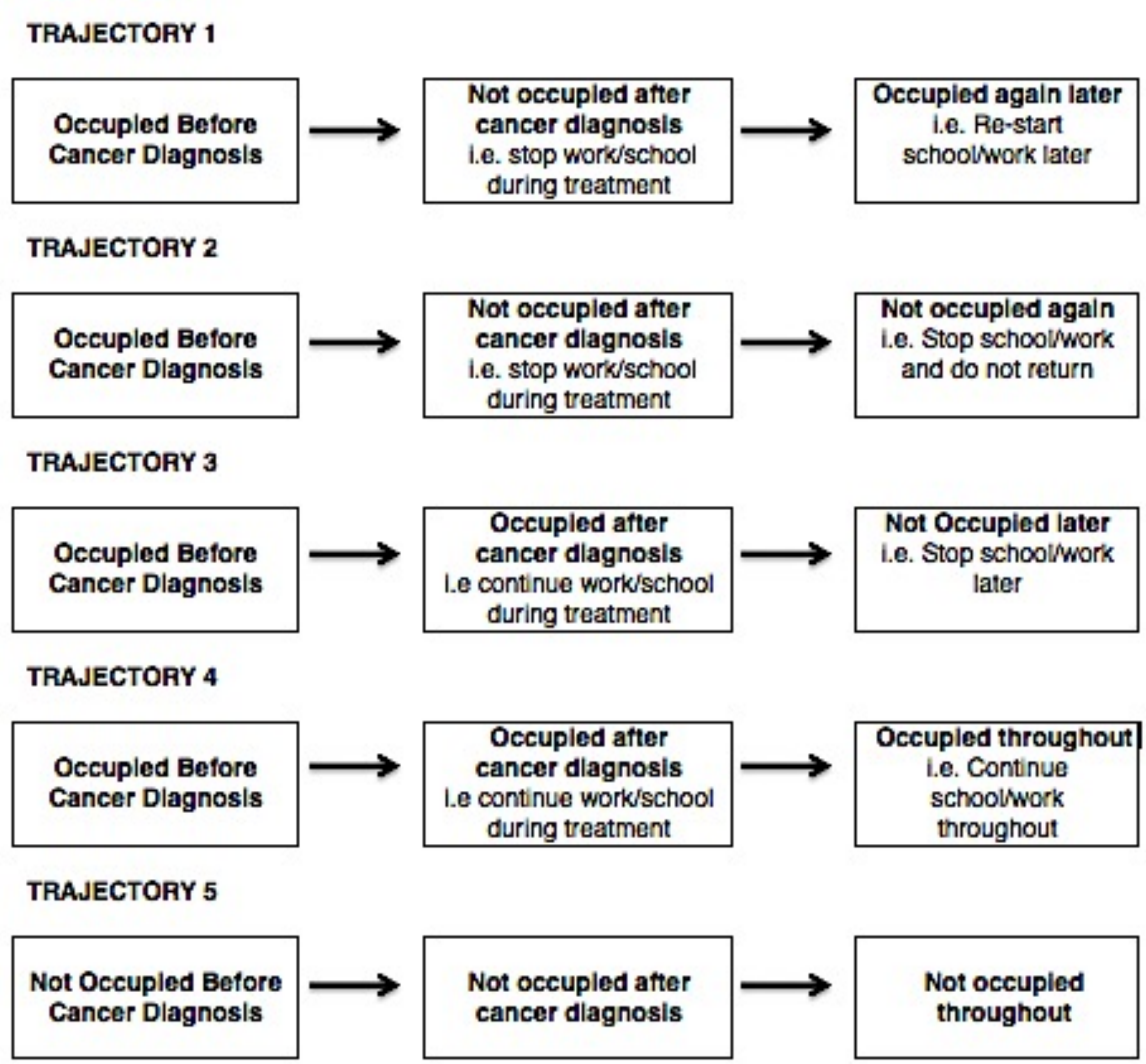


Figure 3. Bonanno's (2004) Stress-Coping Model

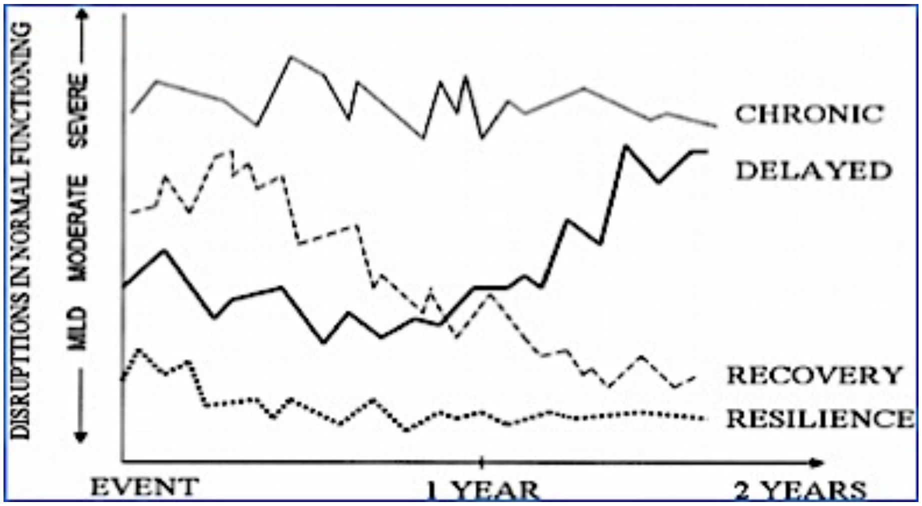


Figure 4. General Trends in Time-Variant Variables

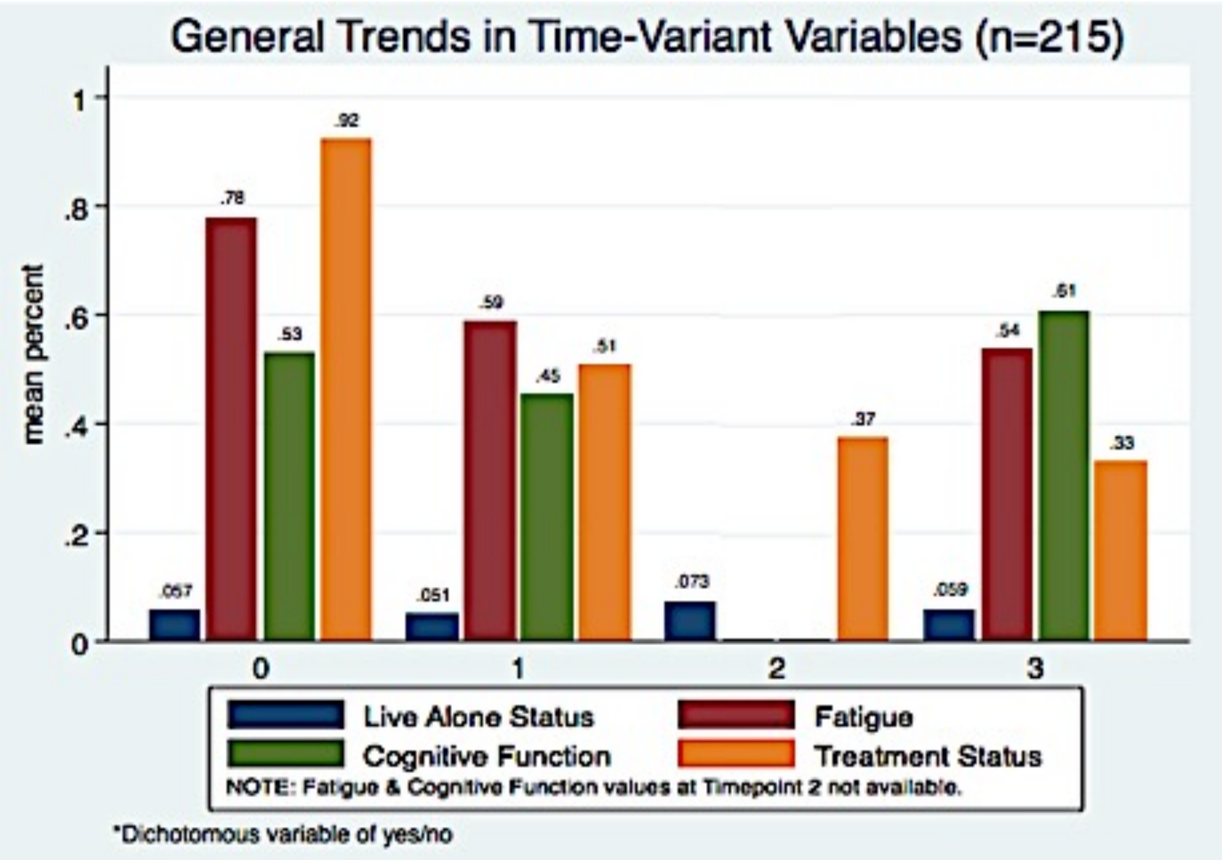


Figure 5. Relationship Between Effect Size and Power

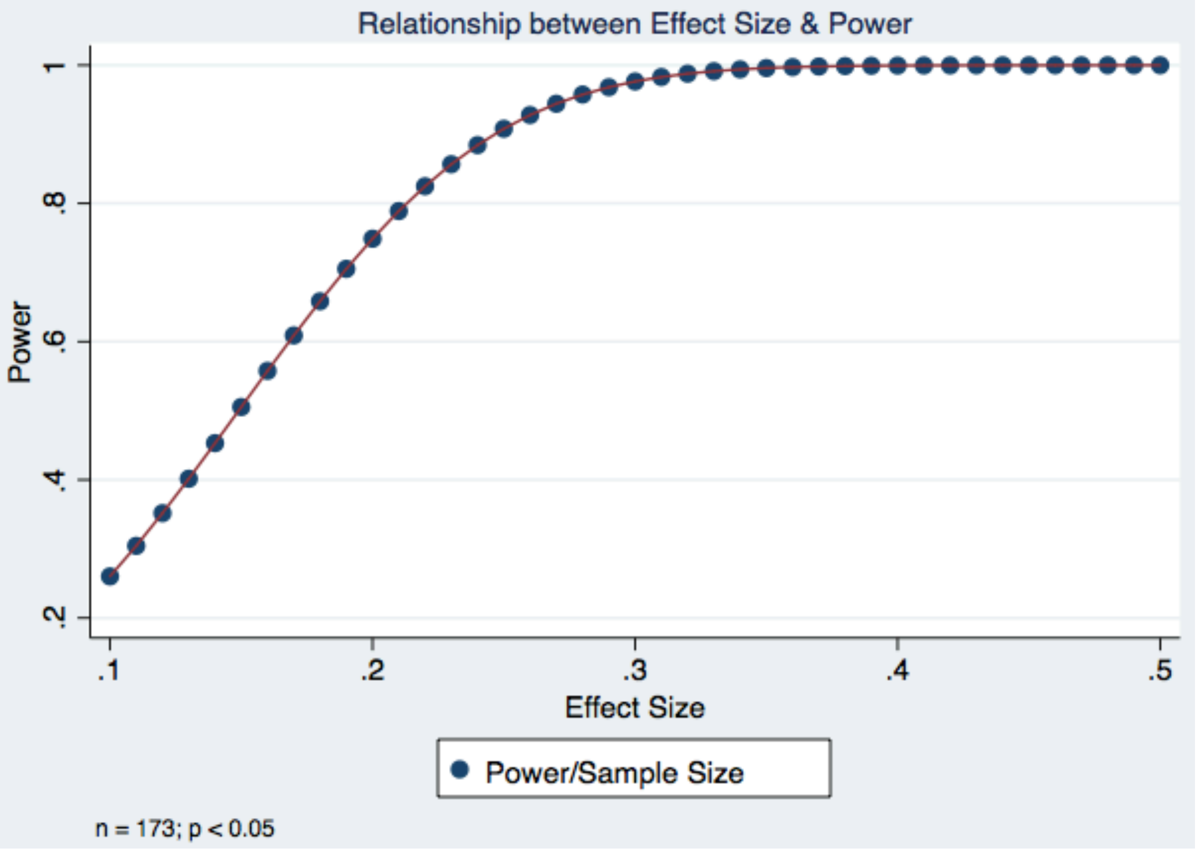


Figure 6. Aim One Conceptual Model for Psychological Distress Trajectory

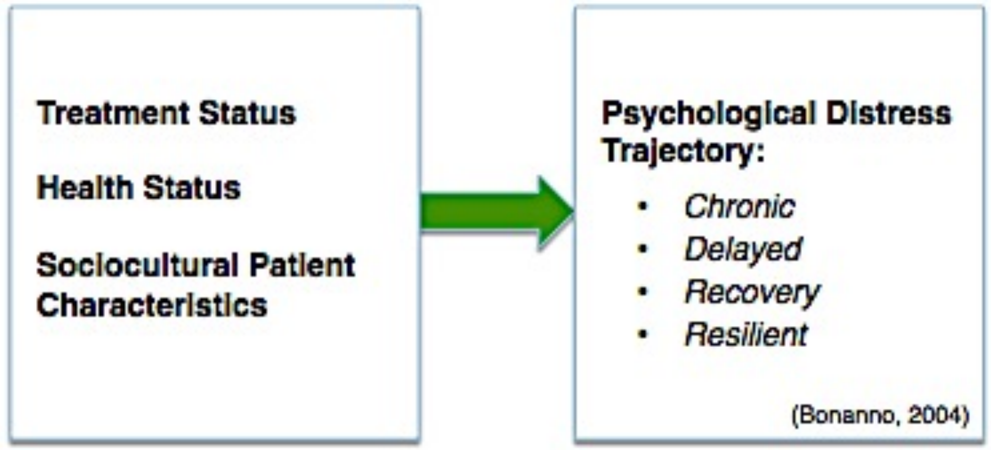


Figure 7. Aim Two Conceptual Model for Employment/Education and Psychological Distress Trajectories

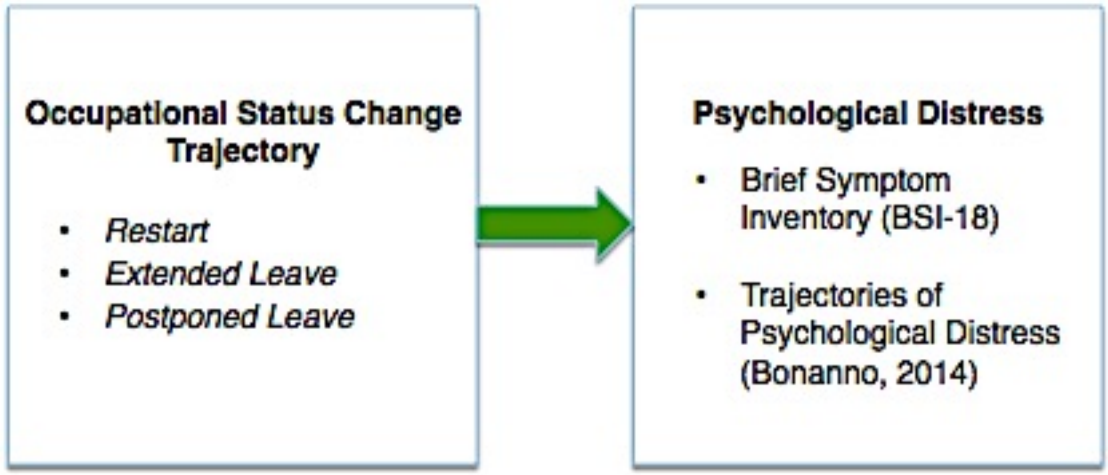
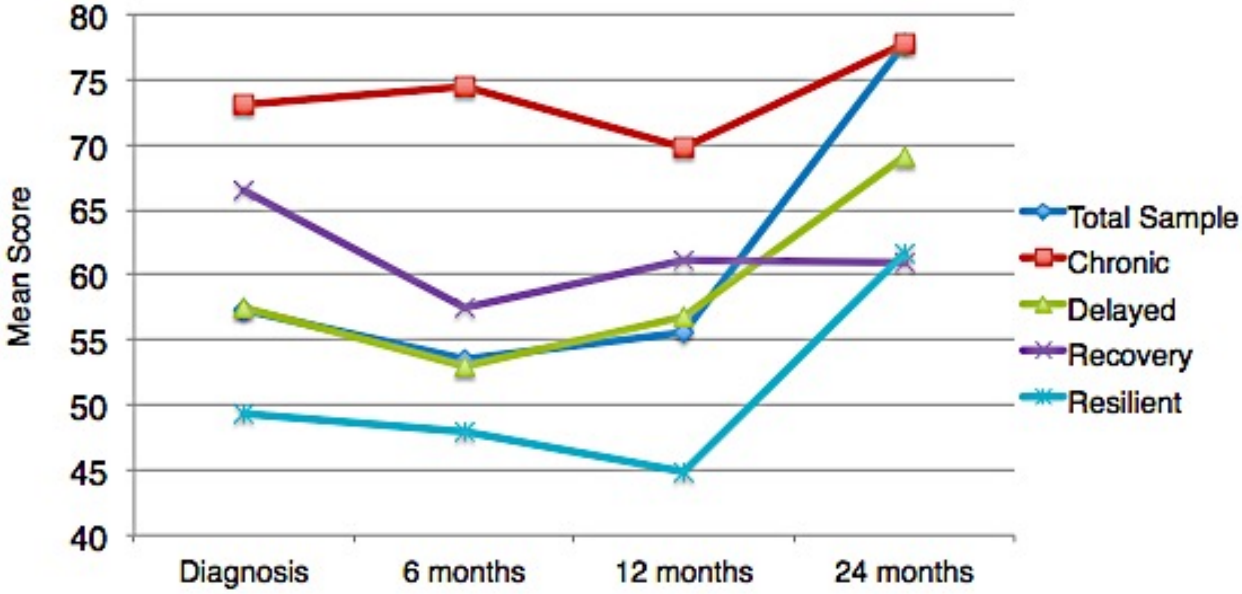


Figure 8. Mean Global Severity Index Scores by Psychological Distress Trajectory (n=173)



	Total Sample (n=173)	Chronic (n=10)	Delayed (n=122)	Recovery (n=8)	Resilient (n=33)
Diagnosis	57	73	57	67	49
6 months	54	74	53	57	48
12 months	56	70	57	61	45
24 months	78	78	69	61	62

Figure 9. Theoretical Trajectories of Occupational Status Change for AYA Cancer Patients

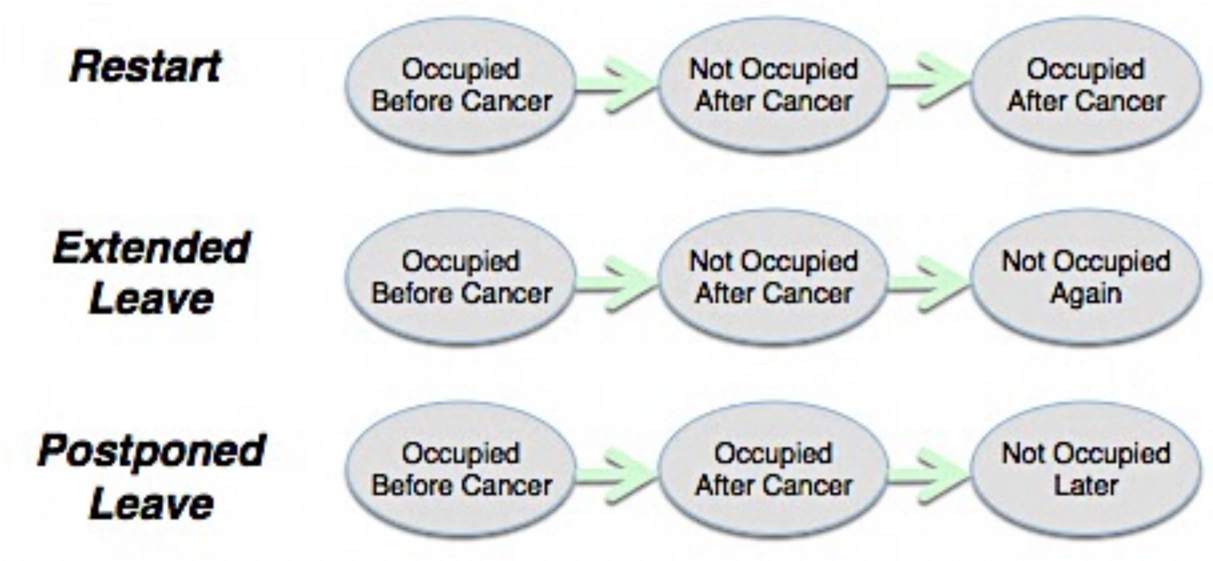
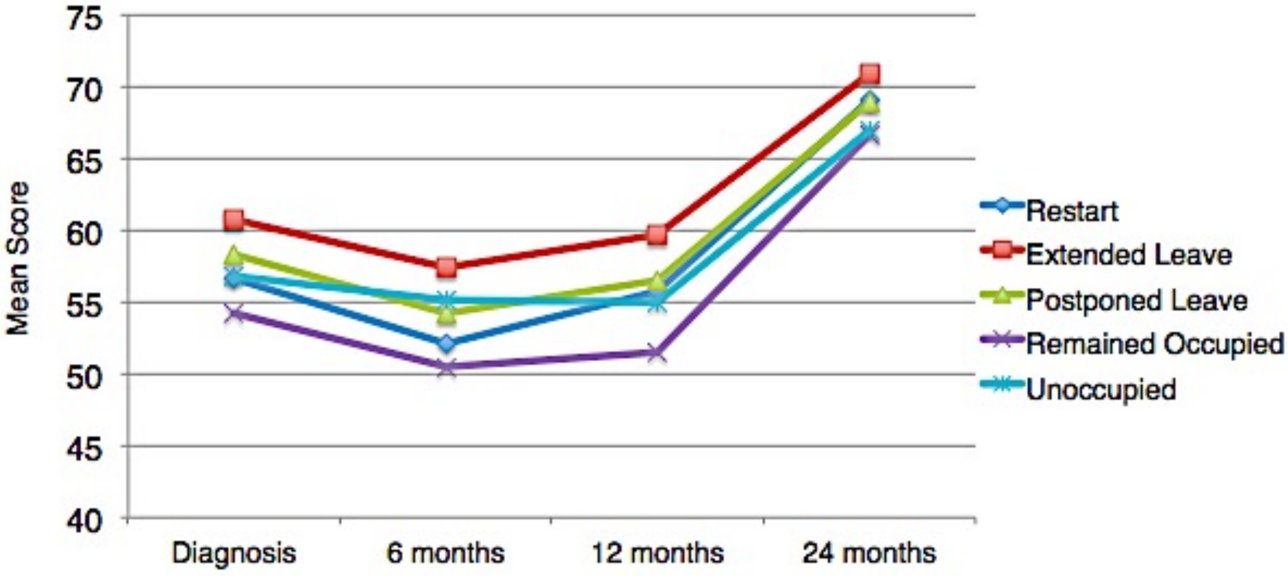
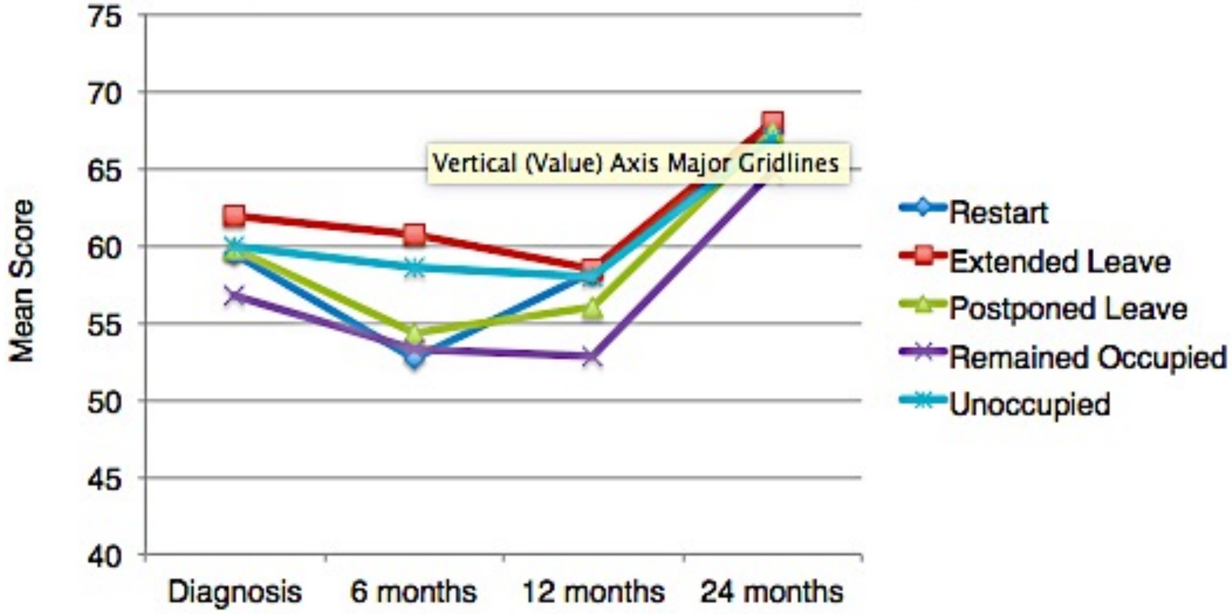


Figure 10. Mean Global Severity Index Scores by Occupational Status Trajectory (n=173)



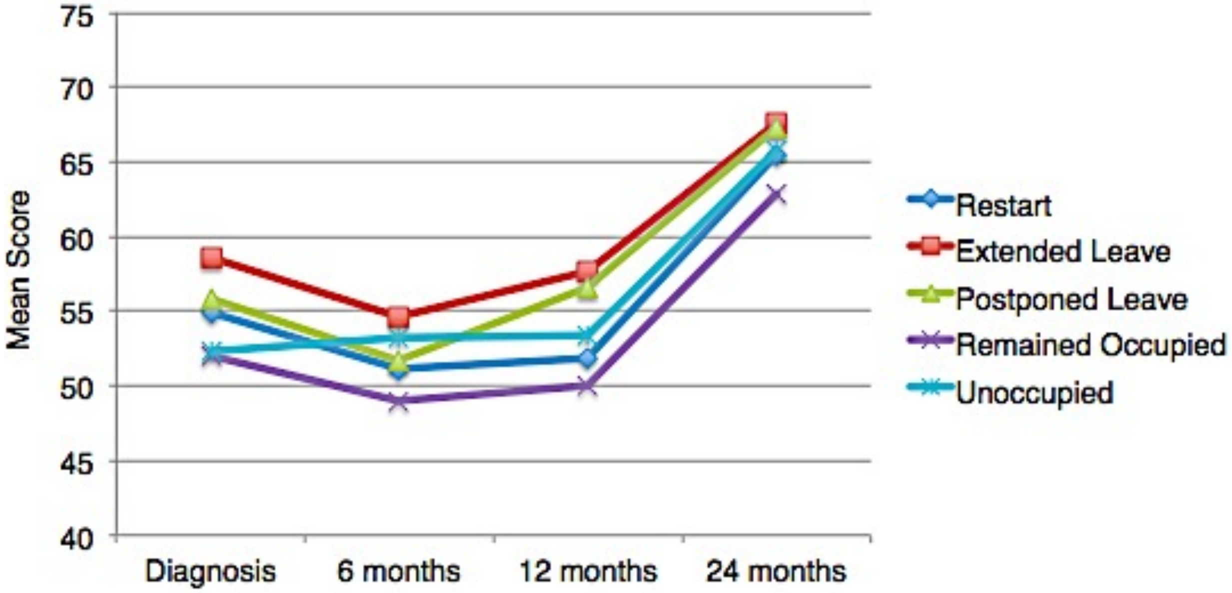
	Restart (n=50)	Extended Leave (n=42)	Postponed Leave (n=19)	Remained Occupied (n=46)	Unoccupied (n=16)
Diagnosis	57	61	58	54	57
6 months	52	57	54	50	55
12 months	56	60	56	51	55
24 months	69	71	69	67	67

Figure 11. Mean Somatization Scores by Occupational Status Trajectory (n=173)



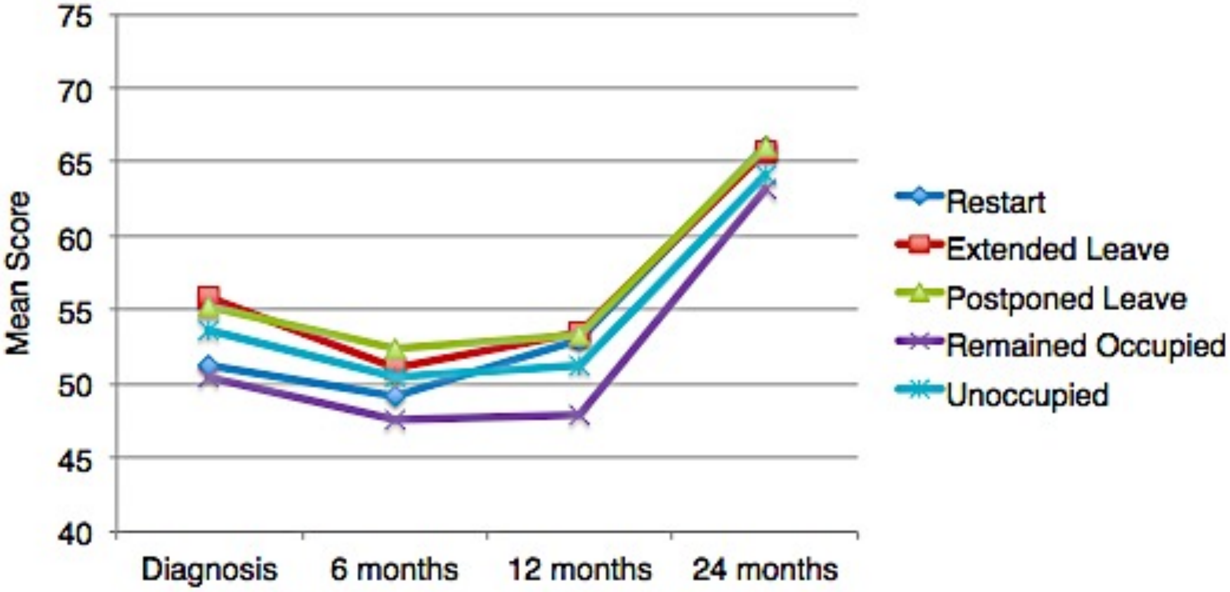
	Restart (n=50)	Extended Leave (n=42)	Postponed Leave (n=19)	Remained Occupied (n=46)	Unoccupied (n=16)
Diagnosis	60	62	60	57	60
6 months	53	61	54	53	59
12 months	58	58	56	53	58
24 months	68	68	67	65	67

Figure 12. Mean Depression Scores by Occupational Status Trajectory (n=173)



	Restart (n=50)	Extended Leave (n=42)	Postponed Leave (n=19)	Remained Occupied (n=46)	Unoccupied (n=16)
Diagnosis	55	59	56	52	52
6 months	51	55	52	49	53
12 months	52	58	57	50	53
24 months	65	68	67	63	66

Figure 13. Mean Anxiety Scores by Occupational Status Trajectory (n=173)



	Restart (n=50)	Extended Leave (n=42)	Postponed Leave (n=19)	Remained Occupied (n=46)	Unoccupied (n=16)
Diagnosis	51	56	55	50	54
6 months	49	51	52	48	50
12 months	53	54	53	48	51
24 months	66	66	66	63	64

Appendix B

TABLES

Table 1. Sociocultural Patient Characteristics of Hopelab Longitudinal Data (Zebrack et al., 2013)

Age	Frequency	Percent
14-17 years	88	41%
18-25 years	43	20%
26-39 years	84	39%
Gender		
Female	101	47%
Male	114	53%
Race/Ethnicity		
White	95	44%
Non-White	118	55%
Live Alone Status		
Live alone	12	6%
Live with spouse/partner	62	29%
Live with children	42	20%
Live with roommate	10	5%
Live with parents	112	52%
Geographic Location		
CHLA	61	28%
OHSU	76	35%
UT	78	36%
Total	215	100%

[a] Participants who self-identified as “Black or African American;” “Asian/Pacific Islander;” “Hispanic/Latino;” or “American Indian/Alaskan Native” in response to the survey, were collapsed into the category “Non-White.”
[b] Some variables do not sum to total n due to missing data

Table 2. Deceased AYA Participants

	6 months after Diagnosis	**12 months after Diagnosis**	**24 months after Diagnosis**
Alive	209(97%)	201(94%)	188(87%)
Deceased	6(3%)	14(6%)	27(13%)
Total	215	215	215

Table 3. Sociocultural Characteristics for AYAs Participants in Current Study Sample (n=173)

Age	Frequency	Percent
14-17 years	77	44%
18-25 years	32	18%
26-39 years	64	37%
Gender		
Female	81	47%
Male	92	53%
Race/Ethnicity - 2 categories		
White	80	47%
Non-White	91	53%
Race/Ethnicity - 5 categories		
White/Caucasian	80	47%
Black or African American	7	4%
Asian/Pacific Islander	9	5%
Hispanic/Latino	73	43%
American Indian/Alaskan Native	2	1%
Live Alone Status		
Live alone	8	5%
Live with spouse/partner	46	27%
Live with children	35	20%
Live with roommate	8	5%
Live with parents	94	55%
Household Income		
< $15,000	46	29%
$15,001-$25,000	23	14%
$25,001-$50,000	37	23%
$50,001-$75,000	22	14%
$75,001-$100,000	9	6%
> $100,000	14	9%
I don't know	9	6%
Geographic Location		
CHLA	51	29%
OHSU	61	35%
UT	61	35%

[a] Participants who self-identified as "Black or African American;" "Asian/Pacific Islander;" "Hispanic/Latino;" or "American Indian/Alaskan Native" in response to the survey, were collapsed into the category "Non-White."
[b] Some variables do not sum to total n due to missing data

Table 4. Cancer Type by Most Common Cancers among AYA (Bleyer, 2011)

	Frequency	Percent
Thyroid	1	1%
Testicular	12	7%
Melanoma	1	1%
Hodgkins	22	13%
Breast	16	9%
Cervical Carcinoma	4	2%
Head/neck carcinoma	8	5%
Non-Hodgkins Lymphoma (NHL)	15	9%
Soft tissue sarcoma	9	5%
Colorectal	3	2%
Osteosarcoma	13	8%
CNS brain	11	6%
Kaposi	1	1%
Ewing	7	4%
Acute Myeloid Leukemia (AML)	10	6%
Acute Lymphoblastic Leukemia (ALL)	31	18%
Rhabdomyosarcoma	6	3%
Adrenocortical carcinoma	1	1%
Hepatic carcinoma	2	1%
Total	173	100

Table 5. Respondents and Non-Respondents

	6 month follow-up			**24 month follow-up**		
	Respondents (n=169)	**Non-Respondents (n=26)**	**X^2 *p* value**	**Respondents (n=141)**	**Non-Respondents (n=74)**	**X^2 *p* value**
Age at diagnosis						
14-17 years	81(92%)	7(8%)	0.01*	68(77%)	20(23%)	0.01*
18-25 years	32(74%)	11(26%)		23(53%)	20(47%)	
26-39 years	66(79%)	18(21%)		50(60%)	34(40%)	
Gender						
Female	84(83%)	17(17%)	0.97	69(68%)	32(32%)	0.43
Male	95(83%)	19(17%)		72(63%)	42(37%)	
Race						
White	78(82%)	17(18%)	0.73	66(69%)	29(31%)	0.30
Non-White[a]	99(84%)	19(16%)		74(63%)	44(37%)	
Geographic Location						
CHLA	58(95%)	3(5%)	0.01*	42(69%)	19(31%)	0.63
OHSU	62(82%)	14(18%)		51(67%)	25(33%)	
UT	59(76%)	19(24%)		48(62%)	30(38%)	
Treatment status						
On Treatment	109(100%)	0(0%)	0.00*	71(100%)	0(0%)	0.00*
Off Treatment	70(66%)	36(34%)		70(49%)	74(51%)	
Type of treatment						
Surgery Only	11(69%)	5(31%)	0.01*	97(44%)	9(56%)	0.00*
Adjuvant Chemo/Radiation	135(84%)	26(16%)		100(62%)	61(38%)	
Ongoing Treatment	33(100%)	0(0%)		33(100%)	0(0%)	

[a] Participants who self-identified as “Black or African American;” “Asian/Pacific Islander;” “Hispanic/Latino;” or “American Indian/Alaskan Native” in response to the survey, were collapsed into the category “Non-White.”

[b] Some variables do not sum to total n due to missing data

*$p < 0.05$

Table 6. Employment Status Across Two Years Following Cancer Diagnosis

	Just before diagnosis	Within 4 months of diagnosis	6 months after diagnosis	24 months after diagnosis
Employed full-time	78(36%)	28(13%)	28(13%)	24(11%)
Employed part-time	17(8%)	11(5%)	13(6%)	13(6%)
Full-time homemaker	77(36%)	4(2%)	2(1%)	4(2%)
Full-time student	5(2%)	42(20%)	45(21%)	49(23%)
On temporary medical leave/disability	5(2%)	46(21%)	22(10%)	13(6%)
Unemployed	28(13%)	59(27%)	56(26%)	28(13%)
Permanently unable to work	2(1%)	18(8%)	9(4%)	3(1%)
Total	211(98%)	208(97%)	175(81%)	137(64%)
Missing	4(2%)	7(3%)	40(19%)	78(36%)

Table 7. Health Status & Treatment Status (n=173)

	Diagnosis	6 months	24 months
	Frequency	Frequency	Frequency
Health Status			
Fatigue			
Yes	134(78%)	67(42%)	63(46%)
No	38(22%)	92(58%)	73(54%)
Cognitive Dysfunction			
Yes	92(54%)	75(47j%)	82(61%)
No	78(46%)	86(53%)	53(39%)
Treatment Status			
On-Treatment	162(94%)	75(47%)	71(41%)
Off-Treatment	11(6%)	86(53%)	102(59%)

[a] Some variables do not sum to total n due to missing data

Table 8. Psychological Distress at Baseline (n=173)

	Mean	Std Dev
BSI-18		
Global Severity Index	57.23	10.09
Somatization	59.44	10.02
Depression	54.90	10.57
Anxiety	52.79	10.42

Table 9. Categorization of AYA Participants by Changes in Psychological Distress (n=173)

Distress Trajectory:	Baseline	6 months	12 months	24 months
Chronic (n=10)				
Missing data:	0	0	5	9
Caseness Patterns:	1	1	1	1
	1	1	1	.
	1	1	.	.
	1	1	.	1
Delayed (n=122)				
Missing data:	0	9	9	3
Caseness Patterns:	0	0	1	1
	0	0	0	1
	0	1	0	1
	0	0	1	.
	0	0	.	1
	0	.	0	1
	0	.	1	1
	1	0	.	1
	1	0	0	1
	0	.	.	1
	0	.	1	.
	0	1	1	1
	0	1	1	.
	0	1	.	1
	0	1	.	.
	1	0	1	1
	1	0	1	.
	1	1	0	1
	1	.	0	1
	1	.	0	1
Recovery (n=8)				
Missing data:	0	0	1	3
Caseness Patterns:	1	0	0	0
	1	1	0	0
	1	0	0	.
	0	1	0	.
	0	.	1	0
	1	1	0	.
	1	.	0	0
	1	0	.	.
	1	1	1	0
Resilient (n=33)				
Missing data:	0	1	10	22
Caseness Trends:	0	0	0	0
	0	0	0	.
	0	.	0	.
	0	0	.	.
	0	.	0	0

1=Caseness for distress; 0=No Caseness for distress; . =Missing data

Based on BSI-18 GSI scores: >63 indicates caseness for distress; </=63 indicates no caseness for distress

[a] For timepoints with missing data, the value from the preceding timepoint was duplicated

Table 10a. Mean GSI Scores by Occupational Status Trajectory

Baseline	Mean	SD	n
Restart	56.64	9.13	50
Extended Leave	60.81	10.04	42
Postponed Leave	58.37	11.09	19
Remained Occupied	54.24	9.15	46
Unoccupied	56.88	12.44	16
Total	57.23	10.09	173
6-month follow-up	**Mean**	**SD**	**n**
Restart	52.1	8.82	48
Extended Leave	57.41	11.35	39
Postponed Leave	54.17	10.55	18
Remained Occupied	50.49	8.96	39
Unoccupied	55.13	12.72	15
Total	53.53	10.33	159

Table 10b. Post-hoc Comparisons Using Bonferroni Correction for Mean GSI Scores by Occupational Status Trajectory

Baseline	Restart	Extended Leave	Postponed Leave	Remained Occupied	F	*p* value
Extended Leave	4.17				2.53	0.04*
Postponed Leave	1.73	-2.44				
Remained Occupied	-2.4	-6.57*	-4.13			
Unoccupied	0.24	-3.93	-1.49	2.64		
6-month follow-up	**Restart**	**Extended Leave**	**Postponed Leave**	**Remained Occupied**	**F**	***p* value**
Extended Leave	5.31				2.67	0.04*
Postponed Leave	2.06	-3.24				
Remained Occupied	-1.62	-6.92*	-3.68			
Unoccupied	3.03	-2.28	0.97	4.65		

*$p<0.05$

Table 11. Sociocultural Patient Characteristics & Psychological Distress Trajectory n=173

	Chronic (n=10)		Delayed (n=122)		Recovery (n=8)		Resilient (n=33)		X^2 *p* value	Fisher's Exact	Cramer's V
Gender	**Freq**	**%**	**Freq**	**%**	**Freq**	**%**	**Freq**	**%**			
Female	5	6%	51	63%	3	4%	22	27%	0.08	0.07	0.20
Male	5	5%	71	77%	5	5%	11	12%			
Race											
White	1	1%	59	74%	1	1%	19	24%	0.02*	0.02	0.24
Non-White	9	10%	62	68%	6	7%	14	15%			
Live Alone Status at Diagnosis											
Not Alone	10	6%	115	71%	7	4%	31	19%	0.62	0.42	0.10
Alone	0	0%	5	63%	1	13%	2	25%			
Geographic Location											
Los Angeles, CA	1	2%	38	75%	3	6%	9	18%	0.38	0.46	0.14
Portland, OR	2	3%	44	72%	2	3%	13	21%			
San Antonio, TX	7	11%	40	66%	3	5%	11	18%			
Household income											
<$15,000	3	21%	9	29%	9	15%	8	17%	0.67	0.80	0.12
$15,000-$50,000	0	0%	1	3%	3	5%	4	9%			
$51,000-$100,000	11	79%	20	65%	43	72%	30	65%			
>$100,000	0	0%	1	3%	5	8%	4	9%			
Treatment Type											
Surgery Only	1	9%	6	55%	1	9%	3	27%	0.91	0.08	0.74
Adjuvant Chemo/Radiation	7	5%	90	70%	6	5%	25	20%			
Ongoing Treatment	2	6%	25	76%	1	3%	5	15%			
Health Status - Fatigue at Diagnosis											
No Fatigue	1	3%	25	66%	1	3%	11	29%	0.23	0.29	0.16
Fatigue	9	7%	97	72%	7	5%	21	16%			
Health Status - Cognitive Function at Diagnosis											
No Cognitive Problems	2	3%	49	63%	6	8%	21	27%	0.01*	0.00	0.27
Cognitive Problems	8	9%	72	78%	2	2%	10	11%			
On/Off Treatment at Diagnosis											
Off Treatment	1	9%	7	64%	1	9%	2	18%	0.85	0.48	0.07
On Treatment	9	6%	115	71%	7	4%	31	19%			
Age	**R-squared**		**F-statistic**		***p* value**						
	0.0434		2.55		0.06						

[a] Participants who self-identified as "Black or African American;" "Asian/Pacific Islander;" "Hispanic/Latino;" or "American Indian/Alaskan Native" in response to the survey, were collapsed into the category "Non-White."

[b] Some variables do not sum to total n due to missing data

**p* < 0.05

Table 12. On/Off Cancer Treatment & Psychological Distress (BSI-18, Global Severity Index Scores)

	Mean	Std Dev	t statistic	*p* value
On/Off Cancer Treatment at Diagnosis (n=173)				
On Treatment (n=162)	57.19	9.99	0.20	0.42
Off Treatment (n=11)	57.82	12.02		
On/Off Cancer Treatment at 6 month (n=159)				
On Treatment (n=95)	53.38	10.37	0.22	0.41
Off Treatment (n=64)	53.75	10.34		
On/Off Cancer Treatment at 12 month (n=150)				
On Treatment (n=69)	58.68	13.13	-2.99	1.00
Off Treatment (n=81)	52.86	10.7		
On/Off Cancer Treatment at 24 months (n=137)				
On Treatment (n=70)	67.90	8.71	1.15	0.13
Off Treatment (n=67)	69.40	6.36		

$^*p < 0.05$

Table 13. Occupational Status Trajectory & Psychological Distress Trajectory (n=173)

	Resilient		**Recovery**		**Delayed**		**Chronic**		**Total**		**X^2 *p* value**	**Cramer's V**
	Freq	%	Freq	%	Freq	%	Freq	%	Freq	%		
Restart	7	14%	2	4%	40	80%	1	2%	50	100%	0.01*	0.22
Extended Leave	4	10%	4	10%	28	67%	6	14%	42	100%		
Postponed Leave	2	11%	0	0%	16	84%	1	5%	19	100%		
Remained Occupied	15	33%	1	2%	30	65%	0	0%	46	100%		
Unoccupied	5	31%	1	6%	8	50%	2	13%	16	100%		
Total	38	22%	7	4%	85	49%	45	26%	175	100%		

$^*p < 0.05$

Table 14. Models of Changes in Psychological Distress (n=173)

Predictors	**Model 1** Main effects only			**Model 2** Main effects & Time-invariant variables			**Model 3** All variables & interactions with timepoint			**Model 4** Non-significant interactions excluded		
Time-Invariant Variables:	Estimate	SE	*p* value	Estimate	SE	*p* value	Estimate	SE	*p* value	Estimate	SE	*p* value
Occupational Trajectory												
Restart	2.40	1.56	0.12	2.26	1.68	0.18	1.94	1.43	0.17	1.74	1.56	0.27
Extended Leave	6.21	1.65	0.00*	5.65	1.83	0.00*	2.96	1.57	0.06	3.47	1.71	0.04*
Postponed Leave	3.57	2.08	0.09	4.66	2.17	0.03*	2.14	1.84	0.25	2.74	2.02	0.17
Unoccupied	2.42	2.24	0.28	2.69	2.35	0.25	0.12	2.00	0.95	0.47	2.18	0.83
Age				0.12	0.08	0.16	0.09	0.07	0.21	0.11	0.08	0.17
Gender												
Male				0.89	1.30	0.49	2.67	1.11	0.02*	1.87	1.21	0.12
Race												
Non-White				1.89	1.71	0.27	3.03	1.46	0.04*	2.33	1.59	0.14
Geographic Location												
OHSU				-0.61	2.22	0.79	0.99	1.89	0.60	0.31	2.06	0.88
UT				-1.51	1.93	0.43	0.31	1.64	0.85	-0.58	1.78	0.75
Household Income												
< $15,000				3.30	2.62	0.21	3.90	2.22	0.08	4.15	2.44	0.09
$15,000-$50,000				1.46	2.46	0.55	1.28	2.09	0.54	1.19	2.29	0.60
$51,000-$100,000				-0.06	2.58	0.43	-0.43	2.19	0.84	0.69	2.40	0.77
Time-Variant Variables:												
Live Alone Status*Timepoint							0.23	1.40	0.87			
Treatment Status*Timepoint							-1.92	0.84	0.02*	-2.45	0.85	0.00*
Fatigue*Timepoint							-3.69	0.79	0.00*	-3.51	0.75	0.00*
Cognitive Function*Timepoint							1.19	0.74	0.11			
Model *p* value	0.0056*			0.0029*			0.0000*			0.0000*		
Wald X^2 Statistic	14.59			29.85			280.74			220.81		
Fit Statistics												
AIC	4767.18			4126.11			3797.09			3864.47		
BIC	4798.20			4190.40			3903.34			3949.66		

[a] Reference groups: remained occupied, female, white, located at CHLA, >$100,000, not living alone, off treatment, no fatigue, no cognitive dysfunction

[b] Participants who self-identified as “Black or African American;” “Asian/Pacific Islander;” “Hispanic/Latino;” or “American Indian/Alaskan Native” in response to the survey, were collapsed into the category “Non-White.”

*$p < 0.05$

Table 15. Models of Changes in Psychological Distress for Consideration of Dropped Data (n=173)

Predictors	**Model 3** All covariates & interactions			**Model 5** No Health Status Covariates i.e. fatigue & cognitive dysfunction			**Model 6** No health status covariates & added 12-month data		
Time-Invariant Variables:	Estimate	SE	*p* value	Estimate	SE	*p* value	Estimate	SE	*p* value
Occupational Trajectory									
Restart	1.94	1.43	0.17	1.87	1.72	0.28	2.38	1.71	1.65
Extended Leave	2.96	1.57	0.06	4.74	1.87	0.01*	5.34	1.87	0.00*
Postponed Leave	2.14	1.84	0.25	3.56	2.22	0.11	4.03	2.21	0.07
Unoccupied	0.12	2.00	0.95	1.78	2.41	0.46	2.25	2.39	0.35
Age	0.09	0.07	0.21	0.15	0.09	0.09	0.15	0.09	0.08
Gender									
Male	2.67	1.11	0.02*	1.81	1.33	0.17	1.51	1.32	0.25
Race									
Non-White	3.03	1.46	0.04*	2.28	1.76	0.19	2.10	1.74	0.23
Geographic Location									
OHSU	0.99	1.89	0.60	0.07	2.28	0.98	-0.26	2.26	0.91
UT	0.31	1.64	0.85	-0.59	1.98	0.76	-0.81	1.96	0.68
Household Income									
< $15,000	3.90	2.22	0.08	4.10	2.68	0.13	4.17	2.66	0.12
$15,000-$50,000	1.28	2.09	0.54	1.66	2.53	0.51	1.41	2.51	0.58
$51,000-$100,000	-0.43	2.19	0.84	0.30	2.65	0.91	0.45	2.62	0.86
Time-Variant Variables:									
Live Alone Status*Timepoint	0.23	1.40	0.87	0.13	1.47	0.93	0.08	1.46	0.96
Treatment Status*Timepoint	-1.92	0.84	0.02*	-3.29	0.87	0.00*	-3.42	0.87	0.00*
Fatigue*Timepoint	-3.69	0.79	0.00*						
Cognitive Function*Timepoint	1.19	0.74	0.11						
Model *p* value	0.0000*			0.0000*			0.0000*		
Wald X^2 Statistic	280.74			170.44			176.18		
Fit Statistics									
AIC	3797.09			3995.07			3975.19		
BIC	3903.34			4084.96			4065.00		

[a] Reference groups: remained occupied, female, white, located at CHLA, >$100,000, not living alone, off treatment, no fatigue, no cognitive dysfunction

[b] Participants who self-identified as “Black or African American;” “Asian/Pacific Islander;” “Hispanic/Latino;” or “American Indian/Alaskan Native” in response to the survey, were collapsed into the category “Non-White.”

*$p < 0.05$

References

Abdollah, F., Sammon, J. D., Majumder, K., Reznor, G., Gandaglia, G., Sood, A., ... & Selvaggi, K. J. (2015). Racial disparities in end-of-life care among patients with prostate cancer: a population-based study. *Journal of the National Comprehensive Cancer Network*, *13*(9), 1131-1138.

Acquaviva, K. D., & Mintz, M. (2010). Perspective: Are we teaching racial profiling? The dangers of subjective determinations of race and ethnicity in case presentations. *Academic Medicine*, *85*(4), 702-705.

Ahles, T. A., Root, J. C., & Ryan, E. L. (2012). Cancer-and cancer treatment–associated cognitive change: An update on the state of the science. *Journal of Clinical Oncology*, JCO-2012.

Albritton, K., & Bleyer, W. A. (2003). The management of cancer in the older adolescent. *European Journal of Cancer*, *39*(18), 2584-2599.

Albritton, K., Caligiuri, M., Anderson, B., Nichols, C., & Ulman, D. (2006). Closing the gap: research and care imperatives for adolescents and young adults with cancer. *Bethesda, MD: Department of Health and Human Services, National Institute of Health, National Cancer Institute, and the LiveStrong Young Adult Alliance*.

Alsop, R. (2008). *The trophy kids grow up: How the millennial generation is shaking up the workplace*. John Wiley & Sons.

American Anthropological Association. (1998). Statement on “race.”

American Cancer Society. (2016a). *Cancer Facts & Figures 2016.* Atlanta, GA: American Cancer Society.

American Cancer Society. (2016b). *Cancer Treatment and Survivorship Facts and Figures 2016-2017.* Atlanta, GA: American Cancer Society.

American Society for Clinical Oncology. (2016). Cancer Topics: Adolescents and Young Adults Patient and Survivor Care. Retrieved from: http://university.asco.org/cancer-care-2015-update-0

Anders, C. K., Hsu, D. S., Broadwater, G., Acharya, C. R., Foekens, J. A., Zhang, Y., ... & Nevins, J. R. (2008). Young age at diagnosis correlates with worse prognosis and defines a subset of breast cancers with shared patterns of gene expression. *Journal of Clinical Oncology*, *26*(20), 3324-3330.

Arnett, J. J. (1999). Adolescent storm and stress, reconsidered. *American psychologist*, *54*(5), 317.

Arnett, J. J. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *American psychologist*, *55*(5), 469.

Arnett, J. J. (2003). Conceptions of the transition to adulthood among emerging adults in American ethnic groups. *New directions for child and adolescent development*, *2003*(100), 63-76.

Arnett, J. J. (2014). *Emerging adulthood: The winding road from the late teens through the twenties*. OUP Us.

Arnett, J. J. (2007). Emerging adulthood: What is it, and what is it good for?. *Child development perspectives*, *1*(2), 68-73.

Aubin, S., Barr, R., Rogers, P., Schacter, B., Bielack, S. S., Ferrari, A., ... & Petrilli, A. S. (2011). What should the age range be for AYA oncology?.

Aziz N.M. (2002). Cancer survivorship research: Challenge and opportunity. *American Society for Nutritional Sciences* 132, 3494S-3503S.

Barofsky, I. (Ed.). (1989). *Work & illness: the cancer patient*. Praeger Publishers.

Barthel, E. M., Spencer, K., Banco, D., Kiernan, E., & Parsons, S. (2016). Is the Adolescent and Young Adult Cancer Survivor at Risk for Late Effects? It Depends on Where You Look. *Journal of adolescent and young adult oncology*, *5*(2), 159-173.

Basow, S. A., & Rubin, L. R. (1999). Gender influences on adolescent development.

Bellizzi, K. M., Smith, A., Schmidt, S., Keegan, T. H., Zebrack, B., Lynch, C. F., ... & Simon, M. (2012). Positive and negative psychosocial impact of being diagnosed with cancer as an adolescent or young adult. *Cancer*, *118*(20), 5155-5162.

Benner, A. E., & Marlow, L. S. (1991). The effect of a workshop on childhood cancer on students' knowledge, concerns, and desire to interact with a classmate with cancer. *Children's Health Care*, *20*(2), 101-107.

Bennett, B., Goldstein, D., Lloyd, A., Davenport, T., & Hickie, I. (2004). Fatigue and psychological distress–exploring the relationship in women treated for breast cancer. *European Journal of Cancer*, *40*(11), 1689-1695.

Behringer, K., Goergen, H., Müller, H., Thielen, I., Brillant, C., Kreissl, S., ... & Shonukan, O. (2016). Cancer-Related Fatigue in Patients With and Survivors of Hodgkin Lymphoma: The Impact on Treatment Outcome and Social Reintegration. *Journal of Clinical Oncology*, *34*(36), 4329-4337.

Bleyer, W. A. (2002). Cancer in older adolescents and young adults: epidemiology, diagnosis, treatment, survival, and importance of clinical trials. *Medical and pediatric oncology*, *38*(1), 1-10.

Bleyer, A. O. L. M., O'leary, M., Barr, R., & Ries, L. A. G. (2006). Cancer epidemiology in older adolescents and young adults 15 to 29 years of age, including SEER incidence and survival: 1975-2000. *Cancer epidemiology in older adolescents and young adults 15 to 29 years of age, including SEER incidence and survival: 1975-2000*.

Bleyer, A. W., & Barr, R. D. (Eds.). (2007). *Cancer in adolescents and young adults*. Springer Science & Business Media.

Bleyer, A., Barr, R., Hayes-Lattin, B., Thomas, D., Ellis, C., & Anderson, B. (2008). The distinctive biology of cancer in adolescents and young adults. *Nature Reviews Cancer*, *8*(4), 288-298.

Bleyer, A. (2011). Latest estimates of survival rates of the 24 most common cancers in adolescent and young adult Americans. *Journal of Adolescent and Young Adult Oncology*, *1*(1), 37–42.

Bonanno, G. A. (2004). Loss, trauma, and human resilience: have we underestimated the human capacity to thrive after extremely aversive events?. *American psychologist*, *59*(1), 20.

Bonneau, J., Lebreton, J., Taque, S., Chappe, C., Bayart, S., Edan, C., & Gandemer, V. (2011). School performance of childhood cancer survivors: mind the teenagers!. *The Journal of pediatrics*, *158*(1), 135-141.

Bouknight, R. R., Bradley, C. J., & Luo, Z. (2006). Correlates of return to work for breast cancer survivors. *Journal of Clinical Oncology*, *24*(3), 345-353.

Bradley, C. J., & Bednarek, H. L. (2002). Employment patterns of long-term cancer survivors. *Psycho‐oncology*, *11*(3), 188-198.

Breakwell, G. M. (2015). *Coping with threatened identities* (Vol. 5). Psychology Press.

Brinthaupt, T. M., & Lipka, R. P. (2002). Understanding early adolescent self and identity: An introduction. *Understanding early adolescent self and identity: Applications and interventions*, 1-21.

Butow, P., Palmer, S., Pai, A., Goodenough, B., Luckett, T., & King, M. (2010). Review of adherence-related issues in adolescents and young adults with cancer. *Journal of Clinical Oncology*, *28*(32), 4800-4809.

Carpentier, M. Y., & Fortenberry, J. D. (2010). Romantic and sexual relationships, body image, and fertility in adolescent and young adult testicular cancer survivors: a review of the literature. *Journal of Adolescent Health*, *47*(2), 115-125.

Centers for Disease Control and Prevention and National Cancer Institute. (2015). *United States Cancer Statistics: 1999–2012 Incidence and Mortality.* Atlanta, GA: U.S. Department of Health and Human Services. Retrieved from: http://www.cdc.gov/uscs

Chan, A., Ng, T., Chan, R. J., Poon, E., & Farid, M. (2016). Are adolescent and young adult cancer patients affected by ‘chemobrain’?: a call for evidence. *Expert Review of Quality of Life in Cancer Care*.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis.* Thousand Oaks, CA: Sage.

Cheung, C. K., & Zebrack, B. (2016). What do adolescents and young adults want from cancer resources? Insights from a Delphi panel of AYA patients. *Supportive Care in Cancer*, 1-8.

Chin, M. H., & Humikowski, C. A. (2002). When is risk stratification by race or ethnicity justified in medical care?. *Academic Medicine*, *77*(3), 202-208.

Chisholm, L., & Hurrelmann, K. (1995). Adolescence in modern Europe. Pluralized transition patterns and their implications for personal and social risks. *Journal of adolescence*, *18*(2), 129.

Choquette, A., & Rennick, J. E. (2016). Back to School After Cancer Treatment. *Cancer Nursing, 39*(5), 393-401.

Colleoni, M., Rotmensz, N., Robertson, C., Orlando, L., Viale, G., Renne, G., ... & Catalano, G. (2002). Very young women (< 35 years) with operable breast cancer: features of disease at presentation. *Annals of Oncology*, *13*(2), 273-279.

Cooper, A. F., Hankins, M., Rixon, L., Eaton, E., & Grunfeld, E. A. (2013). Distinct work-related, clinical and psychological factors predict return to work following treatment in four different cancer types. *Psycho-Oncology*, *22*(3), 659-667.

Corey, A. L., Haase, J. E., Azzouz, F., & Monahan, P. O. (2008). Social support and symptom distress in adolescents/young adults with cancer. *Journal of Pediatric Oncology Nursing*. Retrieved from http://jpo.sagepub.com/content/early/2008/08/04/1043454208321117.short

Cote, J. E., & Levine, C. G. (2014). *Identity, formation, agency, and culture: A social psychological synthesis*. Psychology Press.

Craig, F. (2006). Adolescents and young adults. *Oxford textbook of palliative care for children*, 108-118.

Creswell, J. W., & Clark, V. L. P. (2007). Designing and conducting mixed methods research.

Creswell, J. W. (2013a). *Qualitative inquiry and research design: Choosing among five approaches*. Thousand Oaks, CA: Sage.

Creswell, J. W. (2013b). *Research design: Qualitative, quantitative, and mixed methods approaches*. Thousand Oaks, CA: Sage.

Czado, C. (2004). Lecture 10: Linear Mixed Models (Linear Models with Random Effects) [Powerpoint slides]. Retrieved from https://www.statistics.ma.tum.de/fileadmin/w00bdb/www/czado/lec10.pdf

DeLong, M. D. (2000). Peers' knowledge and attitudes toward a classmate with cancer: An evaluation of a school reintegration program.

De Boer, A. G. E. M., Verbeek, J. H. A. M., Spelten, E. R., Uitterhoeve, A. L. J., Ansink, A. C., De Reijke, T. M., ... & Van Dijk, F. J. H. (2008). Work ability and return-to-work in cancer patients. *British journal of cancer*, *98*(8), 1342-1347.

De Moor, J. S., Mariotto, A. B., Parry, C., Alfano, C. M., Padgett, L., Kent, E. E., ... & Rowland, J. H. (2013). Cancer survivors in the United States: prevalence across the survivorship trajectory and implications for care. *Cancer Epidemiology Biomarkers & Prevention*, *22*(4), 561-570.

Derogatis, L.R. (2001). *Brief Symptom Inventory 18 (BSI-18): Administration, scoring, and procedures manual*. Bloomington, MN: Pearson.

DeSantis, C. E., Siegel, R. L., Sauer, A. G., Miller, K. D., Fedewa, S. A., Alcaraz, K. I., & Jemal, A. (2016). Cancer statistics for African Americans, 2016: Progress and opportunities in reducing racial disparities. *CA: a cancer journal for clinicians*.

DiAngelo, R. (2011). White fragility. *The International Journal of Critical Pedagogy*, *3*(3).

Dooley, D. (2003). Unemployment, underemployment, and mental health: Conceptualizing employment status as a continuum. *American journal of community psychology*, *32*(1-2), 9-20.

Dorland, H. F., Abma, F. I., Roelen, C. A. M., Smink, J. G., Ranchor, A. V., & Bültmann, U. (2016). Factors influencing work functioning after cancer diagnosis: a focus group study with cancer survivors and occupational health professionals. *Supportive Care in Cancer*, *24*(1), 261-266.

Drabe, N., Steinert, H., Moergeli, H., Weidt, S., Strobel, K., & Jenewein, J. (2016). Perception of treatment burden, psychological distress, and fatigue in thyroid cancer patients and their partners–effects of gender, role, and time since diagnosis. *Psycho-Oncology*, *25*(2), 203-209.

Duijts, S. F., Egmond, M. P., Spelten, E., Muijen, P., Anema, J. R., & Beek, A. J. (2014). Physical and psychosocial problems in cancer survivors beyond return to work: a systematic review. *Psycho-Oncology*, *23*(5), 481-492.

Durani, U., & Go, R. S. (2017). Racial and ethnic disparities in the survival of adolescents and young adults with acute myeloid leukemia: a retrospective study using the US National Cancer Data Base. *Leukemia & Lymphoma*, *58*(5), 1184-1189.

Eccles, J. S., Wong, C. A., & Peck, S. C. (2006). Ethnicity as a social context for the development of African-American adolescents. *Journal of School Psychology*, *44*(5), 407-426.

Eggly, S., Barton, E., Winckles, A., Penner, L. A., & Albrecht, T. L. (2015). A disparity of words: racial differences in oncologist–patient communication about clinical trials. *Health Expectations*, *18*(5), 1316-1326.

Ehrmann-Feldmann, D., Spitzer, W. O., Del Greco, L., & Desmeules, L. (1987). Perceived discrimination against cured cancer patients in the work force. *CMAJ: Canadian Medical Association Journal*, *136*(7), 719.

Erickson, J. M., MacPherson, C. F., Ameringer, S., Baggott, C., Linder, L., & Stegenga, K. (2013). Symptoms and symptom clusters in adolescents receiving cancer treatment: a review of the literature. *International journal of nursing studies*, *50*(6), 847-869.

Erikson, E. H. (1959). Identity and the life cycle: Selected papers. *Psychological issues*.

Evan, E. E., Kaufman, M., Cook, A. B., & Zeltzer, L. K. (2006). Sexual health and self-esteem in adolescents and young adults with cancer. *Cancer*, *107*(S7), 1672-1679.

Evan, E. E., & Zeltzer, L. K. (2006). Psychosocial dimensions of cancer in adolescents and young adults. *Cancer*, *107*(S7), 1663-1671.

Fan, Y., & Li, R. (2012). Variable selection in linear mixed effects models. *Annals of statistics*, *40*(4), 2043.

Faul, F., Erdfelder, E., Buchner, A., & Lang, A.-G. (2013). G*Power Version 3.1.7 [computer software]. Uiversität Kiel, Germany. Retrieved from http://www.psycho.uni-duesseldorf.de/abteilungen/aap/gpower3/download-and-register

Fava, M., Ball, S., Nelson, J. C., Sparks, J., Konechnik, T., Classi, P., ... & Thase, M. E. (2014). Clinical relevance of fatigue as a residual symptom in major depressive disorder. *Depression and anxiety*, *31*(3), 250-257.

Field, A. (2009). *Discovering statistics using SPSS*. Sage publications.

Ganz, P. A. (1990). Current issues in cancer rehabilitation. *Cancer*, *65*(S3), 742-751.

Geiger, A. M., & Castellino, S. M. (2011). Delineating the age ranges used to define adolescents and young adults. *Journal of Clinical Oncology*, *29*(16), 492–e493.

Georgiadi, M., & Kourkoutas, E. E. (2010). Supporting pupils with cancer on their return to school: a case study report of a reintegration program. *Procedia-Social and Behavioral Sciences*, *5*, 1278-1282.

Giuntoli, G., Hughes, S., Karban, K., & South, J. (2014). Towards a middle-range theory of mental health and well-being effects of employment transitions: Findings from a qualitative study on unemployment during the 2009–2010 economic recession. *Health:*, 1363459314554314.

Goodman, A. H. (2000). Why genes don't count (for racial differences in health). *American Journal of Public Health*, *90*(11), 1699.

Goyal, M. K., Kuppermann, N., Cleary, S. D., Teach, S. J., & Chamberlain, J. M. (2015). Racial disparities in pain management of children with appendicitis in emergency departments. *JAMA pediatrics*, *169*(11), 996-1002.

Graham, J. (2013, Nov 4) A generation of idle trophy kids. *Boston Globe.* Retrieved from https://www.bostonglobe.com/opinion/2013/11/04/idle-millennials-are-victims-their-parents-success/2rWDFWXQHo290FqUpz0HOO/story.html

Greene, A. L., Wheatley, S. M., & Aldava, J. F. (1992). Stages on Life's Way Adolescents' Implicit Theories of the Life Course. *Journal of Adolescent Research*, *7*(3), 364-381.

Green, C. R., Anderson, K. O., Baker, T. A., Campbell, L. C., Decker, S., Fillingim, R. B., ... & Todd, K. H. (2003). The unequal burden of pain: confronting racial and ethnic disparities in pain. *Pain medicine*, *4*(3), 277-294.

Grinyer, A. (2007). *Young people living with cancer: Implications for policy and practice*. McGraw-Hill Education (UK).

Groeneveld, I. F., de Boer, A. G., & Frings-Dresen, M. H. (2013). Physical exercise and return to work: cancer survivors' experiences. *Journal of Cancer Survivorship*, *7*(2), 237-246.

Gummadam, P., Pittman, L. D., & Ioffe, M. (2016). School Belonging, Ethnic Identity, and Psychological Adjustment Among Ethnic Minority College Students. *The Journal of Experimental Education*, *84*(2), 289-306.

Guy, G. P., Yabroff, K. R., Ekwueme, D. U., Smith, A. W., Dowling, E. C., Rechis, R., ... & Richardson, L. C. (2014). Estimating the health and economic burden of cancer among those diagnosed as adolescents and young adults. *Health Affairs*, *33*(6), 1024-1031.

Haase, J. E., & Phillips, C. R. (2004). The adolescent/young adult experience. *Journal of Pediatric Oncology Nursing*, *21*(3), 145–149.

Hankin, B. L., & Abramson, L. Y. (2001). Development of gender differences in depression: An elaborated cognitive vulnerability–transactional stress theory. *Psychological bulletin*, *127*(6), 773.

Harlan, L. C., Lynch, C. F., Keegan, T. H., Hamilton, A. S., Wu, X. C., Kato, I., ... & Deapen, D. (2011). Recruitment and follow-up of adolescent and young adult cancer survivors: the AYA HOPE Study. *Journal of Cancer Survivorship*, *5*(3), 305-314.

Harris, A. P. (2000). Gender, violence, race, and criminal justice. *Stanford Law Review*, 777-807.

Hays, D. M. (1993). Adult survivors of childhood cancer employment and insurance issues in different age groups. *Cancer*, *71*(S10), 3306-3309.

Hedeker, D., & Gibbons, R. D. (2006). *Longitudinal data analysis* (Vol. 451). John Wiley & Sons.

Hirsh, A. T., Hollingshead, N. A., Ashburn-Nardo, L., & Kroenke, K. (2015). The interaction of patient race, provider bias, and clinical ambiguity on pain management decisions. *The Journal of Pain*, *16*(6), 558-568.

Hoffman, R. M., Gilliland, F. D., Eley, J. W., Harlan, L. C., Stephenson, R. A., Stanford, J. L., ... & Potosky, A. L. (2001). Racial and ethnic differences in advanced-stage prostate cancer: the Prostate Cancer Outcomes Study. *Journal of the National Cancer Institute*, *93*(5), 388-395.

Hout, M. (2012). Social and economic returns to college education in the United States. *Annual Review of Sociology*, *38*, 379-400.

Hoving, J. L., Broekhuizen, M. L. A., & Frings-Dresen, M. H. W. (2009). Return to work of breast cancer survivors: a systematic review of intervention studies. *BMC cancer*, *9*(1), 1.

Howard-Anderson, J., Ganz, P. A., Bower, J. E., & Stanton, A. L. (2012). Quality of life, fertility concerns, and behavioral health outcomes in younger breast cancer survivors: a systematic review. *Journal of the National Cancer Institute*, *104*(5), 386–405.

Howe, N., & Strauss, W. (2009). *Millennials rising: The next great generation*. Vintage.

Hunt, L. M., Truesdell, N. D., & Kreiner, M. J. (2013). Genes, Race, and Culture in Clinical Care. *Medical anthropology quarterly*, *27*(2), 253-271.

Husson, O., & Zebrack, B. J. (2016). Psychometric Evaluation of an Adolescent and Young Adult Module of the Impact of Cancer Instrument.*Journal of Adolescent and Young Adult Oncology*.

Husson, O., Zebrack, B. J., Aguilar, C., Hayes-Lattin, B., & Cole, S. (2017). Cancer in adolescents and young adults: Who remains at risk of poor social functioning over time?. *Cancer*.

Husson, O., Zebrack, B. J., Block, R., Embry, L., Aguilar, C., Hayes-Lattin, B., & Cole, S. (2017). Health-related quality of life in adolescent and young adult patients with cancer: a longitudinal study. *Journal of Clinical Oncology*, *35*(6), 652-659.

Johnson, S. B., Blum, R. W., & Giedd, J. N. (2009). Adolescent maturity and the brain: the promise and pitfalls of neuroscience research in adolescent health policy. *Journal of Adolescent Health*, *45*(3), 216-221.

Kahn, J. M., Keegan, T. H., Tao, L., Abrahão, R., Bleyer, A., & Viny, A. D. (2016). Racial disparities in the survival of American children, adolescents, and young adults with acute lymphoblastic leukemia, acute myelogenous leukemia, and Hodgkin lymphoma. *Cancer*, *122*(17), 2723-2730.

Kaplan, R. M., & Milstein, A. (2016). Financial Strain and Cancer Outcomes. *Journal of Clinical Oncology*, JCO668079.

Katz, A. J., Chia, V. M., Schoonen, W. M., & Kelsh, M. A. (2015). Acute lymphoblastic leukemia: an assessment of international incidence, survival, and disease burden. *Cancer Causes & Control*, *26*(11), 1627-1642.

Kearney, C. A. (2008). School absenteeism and school refusal behavior in youth: A contemporary review. *Clinical psychology review*, *28*(3), 451-471.

Keegan, T. H., Tao, L., DeRouen, M. C., Wu, X. C., Prasad, P., Lynch, C. F., ... & Smith, A. W. (2014). Medical care in adolescents and young adult cancer survivors: what are the biggest access-related barriers?. *Journal of Cancer Survivorship*, *8*(2), 282-292.

Kelly, D., Pearce, S., & Mulhall, A. (2004). ‘Being in the same boat’: ethnographic insights into an adolescent cancer unit. *International journal of nursing studies*, *41*(8), 847-857.

Kirchhoff, A. C., Lyles, C. R., Fluchel, M., Wright, J., & Leisenring, W. (2012). Limitations in health care access and utilization among long-term survivors of adolescent and young adult cancer. *Cancer*, *118*(23), 5964-5972.

Kwak, M., Zebrack, B. J., Meeske, K. A., Embry, L., Aguilar, C., Block, R., ... & Cole, S. (2013). Trajectories of psychological distress in adolescent and young adult patients with cancer: a 1-year longitudinal study. *Journal of clinical oncology*, *31*(17), 2160-2166.

Kwate, N. O. A., & Goodman, M. S. (2014). An empirical analysis of White privilege, social position and health. *Social science & medicine*, *116*, 150-160.

Langeveld, N. E., Ubbink, M. C., Last, B. F., Grootenhuis, M. A., Voute, P. A., & De Haan, R. J. (2003). Educational achievement, employment and living situation in long-term young adult survivors of childhood cancer in the Netherlands. *Psycho-Oncology*, *12*(3), 213-225.

Langford, A. T., Resnicow, K., Dimond, E. P., Denicoff, A. M., Germain, D. S., McCaskill-Stevens, W., ... & Go, R. S. (2014). Racial/ethnic differences in clinical trial enrollment, refusal rates, ineligibility, and reasons for decline among patients at sites in the National Cancer Institute's Community Cancer Centers Program. *Cancer, 120*(6), 877-884.

Lopez, C. M., Andrews III, A. R., Chisolm, A. M., de Arellano, M. A., Saunders, B., & Kilpatrick, D. G. (2016). Racial/Ethnic Differences in Trauma Exposure and Mental Health Disorders in Adolescents.

Luhby, T. (2014, June 30). Enough with Millenials. Here’s what Gen X thinks. *CNN Money.* Retrieved from: http://money.cnn.com/2014/06/30/news/economy/gen-x/

Lupien, S. J., McEwen, B. S., Gunnar, M. R., & Heim, C. (2009). Effects of stress throughout the lifespan on the brain, behaviour and cognition. *Nature Reviews Neuroscience*, *10*(6), 434-445.

Mak, A. K. Y., Chaidaroon, S., Fan, G., & Thalib, F. (2014). Unintended consequences: the social context of cancer survivors and work. *Journal of Cancer Survivorship*, *8*(2), 269-281.

Mallinckrodt, B., Armer, J. M., & Heppner, P. P. (2012). A threshold model of social support, adjustment, and distress after breast cancer treatment. *Journal of counseling psychology*, *59*(1), 150.

Marchand, A., Demers, A., & Durand, P. (2005). Does work really cause distress? The contribution of occupational structure and work organization to the experience of psychological distress. *Social Science & Medicine*, *61*(1), 1-14.

Maruthappu, M., Watkins, J., Noor, A. M., Williams, C., Ali, R., Sullivan, R., ... & Atun, R. (2016). Economic downturns, universal health coverage, and cancer mortality in high-income and middle-income countries, 1990–2010: a longitudinal analysis. *The Lancet*.

Mason, M. (2010). Sample Size and Saturation in PhD Studies Using Qualitative Interviews. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, *11*(3). Retrieved from http://nbn-resolving.de/urn:nbn:de:0114-fqs100387

McDowell, L. (2014). The Sexual Contract, Youth, Masculinity and the Uncertain Promise of Waged Work in Austerity Britain. *Australian Feminist Studies*, *29*(79), 31-49.

McHorney, C. A. (1999). Health status assessment methods for adults: Past accomplishments and future challenges 1. *Annual review of public health*,*20*(1), 309-335.

Meadows, A., Massari, D., Fergusson, J., Gordon, J., Littman, P., & Moss, K. (1981). Declines in IQ scores and cognitive dysfunctions in children with acute lymphocytic leukaemia treated with cranial irradiation. *The lancet*, *318*(8254), 1015-1018.

Mehnert, A., de Boer, A., & Feuerstein, M. (2013). Employment challenges for cancer survivors. *Cancer*, *119*(S11), 2151-2159.

Meyer, I. H. (2003). Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations: conceptual issues and research evidence. *Psychological bulletin*, *129*(5), 674.

Morgan, D. L. (1998). Practical strategies for combining qualitative and quantitative methods: Applications to health research. *Qualitative health research*, *8*(3), 362-376.

Morgan, S., Davies, S., Palmer, S., & Plaster, M. (2010). Sex, drugs, and rock 'n'roll: caring for adolescents and young adults with cancer. *Journal of Clinical Oncology*, *28*(32), 4825-4830.

Moran, J. R., Short, P. F., & Hollenbeak, C. S. (2011). Long-term employment effects of surviving cancer. *Journal of health economics*, *30*(3), 505-514.

Morse, J. M. (1994). Designing funded qualitative research.

In Denzin, Norman K. (Ed); Lincoln, Yvonna S. (Ed). (1994). Handbook of qualitative research , (pp. 220-235). Thousand Oaks, CA, US: Sage Publications.

Moskowitz, M. C., Todd, B. L., Chen, R., & Feuerstein, M. (2014). Function and friction at work: a multidimensional analysis of work outcomes in cancer survivors. *Journal of Cancer Survivorship*, *8*(2), 173-182.

Muijen, P., Weevers, N. L. E. C., Snels, I. A. K., Duijts, S. F. A., Bruinvels, D. J., Schellart, A. J. M., & Beek, A. J. (2013). Predictors of return to work and employment in cancer survivors: a systematic review. *European journal of cancer care*, *22*(2), 144-160.

Munir, F., Yarker, J., Haslam, C., Long, H., Leka, S., Griffiths, A., & Cox, S. (2007). Work factors related to psychological and health-related distress among employees with chronic illnesses. *Journal of occupational rehabilitation*, *17*(2), 259-277.

Nachreiner N. M., Dagher, R. K., McGovern P. M, Baker, B. A., Alexander, B. H., & Gerberich, S.G. (2007). Successful return to work for cancer survivors. *Workplace Health & Safety*, *55*(7), 290.

National Cancer Institute. (2016) Surveillance, Epidemiology, and End Results (SEER) Program. *SEER*Stat Database: 13 Areas.* Retrieved from http://www.seer.cancer.gov

National Cancer Institute. (2017). *Dictionary of Cancer Terms*. Retrieved from http://www.cancer.gov/dictionary.

Nawaz, H., & Brett, A. S. (2009). Mentioning race at the beginning of clinical case presentations: a survey of US medical schools. *Medical education*, *43*(2), 146-154.

Nellis, R. (2012). Implications of cancer survivorship on wages, work productivity, and employment circumstances. (Unpublished master's thesis). Georgetown University, Washington, DC.

Nolen-Hoeksema, S., & Girgus, J. S. (1994). The emergence of gender differences in depression during adolescence. *Psychological bulletin*, *115*(3), 424.

Noll, R. B., Gartstein, M. A., Vannatta, K., Correll, J., Bukowski, W. M., & Davies, W. H. (1999). Social, emotional, and behavioral functioning of children with cancer. *Pediatrics*, *103*(1), 71-78.

Pang, J. W., Friedman, D. L., Whitton, J. A., Stovall, M., Mertens, A. C., Robison, L. L., & Weiss, N. S. (2008). Employment status among adult survivors in the Childhood Cancer Survivor Study. *Pediatric blood & cancer*, *50*(1), 104-110.

Peipins, L. A., Soman, A., Berkowitz, Z., & White, M. C. (2012). The lack of paid sick leave as a barrier to cancer screening and medical care-seeking: results from the National Health Interview Survey. *BMC public health*, *12*(1), 520.

Peteet, J. R. (2000). Cancer and the meaning of work. *General hospital psychiatry*, *22*(3), 200-205.

Pew Research Center. (2010). *Millenials: A portrait of generation next.* Washington, D.C.: American Cancer Society. Retrieved from http://www.pewsocialtrends.org/files/2010/10/millennials-confident-connected-open-to-change.pdf

Phinney, J. S. (1989). Stages of ethnic identity development in minority group adolescents. *The Journal of Early Adolescence*, *9*(1-2), 34-49.

Phinney, J. S. (1991). Ethnic identity and self-esteem: A review and integration. *Hispanic journal of behavioral sciences*, *13*(2), 193-208.

Pisu, M., Kenzik, K. M., Oster, R. A., Drentea, P., Ashing, K. T., Fouad, M., & Martin, M. Y. (2015). Economic hardship of minority and non-minority cancer survivors 1 year after diagnosis: Another long-term effect of cancer?. *Cancer*, *121*(8), 1257-1264.

Poort, H., Kaal, S., Knoop, H., Jansen, R., Prins, J., Manten-Horst, E., ... & Van der Graaf, W. (2017). Severe fatigue in adolescent and young adult (AYA) cancer patients: prevalence, impact on quality of life (QOL), and associated factors. *European Journal of Cancer*, *72*, S171.

Priest, N., Paradies, Y., Trenerry, B., Truong, M., Karlsen, S., & Kelly, Y. (2013). A systematic review of studies examining the relationship between reported racism and health and wellbeing for children and young people. *Social science & medicine*, *95*, 115-127.

Rabe-Hesketh, S., & Skrondal, A. (2008). *Multilevel and longitudinal modeling using Stata*. STATA press.

Reid-Arndt, S. A., Yee, A., Perry, M. C., & Hsieh, C. (2009). Cognitive and psychological factors associated with early posttreatment functional outcomes in breast cancer survivors. *Journal of psychosocial oncology*, *27*(4), 415-434.

Reinertsen, K. V., Engebraaten, O., Loge, J. H., Cvancarova, M., Naume, B., Wist, E., ... & Kiserud, C. E. (2017). Fatigue During and After Breast Cancer Therapy—A Prospective Study. *Journal of pain and symptom management*, *53*(3), 551-560.

Ritchie, J., Lewis, J., Nicholls, C. M., & Ormston, R. (Eds.). (2013). *Qualitative research practice: A guide for social science students and researchers*. Sage.

Rowe, J. M., Buck, G., Burnett, A. K., Chopra, R., Wiernik, P. H., Richards, S. M., ... & Prentice, H. G. (2005). Induction therapy for adults with acute lymphoblastic leukemia: results of more than 1500 patients from the international ALL trial: MRC UKALL XII/ECOG E2993. *Blood*, *106*(12), 3760-3767.

Russell, G. M., & Kelly, N. H. (2002). Research as Interacting Dialogic Processes: Implications for Reflexivity. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, *3*(3).

Sabin, D. J. A., Nosek, D. B. A., Greenwald, D. A. G., & Rivara, D. F. P. (2009). Physicians' implicit and explicit attitudes about race by MD race, ethnicity, and gender. *Journal of Health Care for the Poor and Underserved*, *20*(3), 896.

Sandelowski, M., & Barroso, J. (2003). Writing the proposal for a qualitative methodology project. Qualitative Health Research, 13(6), 781-820.

Sateren, W. B., Trimble, E. L., Abrams, J., Brawley, O., Breen, N., Ford, L., ... & Christian, M. C. (2002). How sociodemographics, presence of oncology specialists, and hospital cancer programs affect accrual to cancer treatment trials. *Journal of Clinical Oncology*, *20*(8), 2109-2117.

Scheer, S. D., Unger, D. G., & Brown, M. B. (1996). Adolescents becoming adults: Attributes for adulthood. *Adolescence*, *31*(121), 127.

Schawbel, D. (2012, March 29). Millennials vs. baby boomers: Who would you rather hire? *Time.* Retrieved from http://business.time.com/2012/03/29/millennials-vs-baby-boomers-who-would-you-rather-hire/

Schover, L. R., Jenkins, R., Sui, D., Adams, J. H., Marion, M. S., & Jackson, K. E. (2006). Randomized trial of peer counseling on reproductive health in African American breast cancer survivors. *Journal of Clinical Oncology*, *24*(10), 1620-1626.

Self, M. C. (2007). Surviving with Scars: The Long-Term Psychosocial Consequences of Teenage Cancer. *Cancer and the Adolescent, Second Edition*, 183-200.

Sender, L., & Zabokrtsky, K. B. (2015). Adolescent and young adult patients with cancer: a milieu of unique features. *Nature Reviews Clinical Oncology*, *12*(8), 465-480.

Shahid, A., Chung, S. A., Maresky, L., Danish, A., Bingeliene, A., Shen, J., & Shapiro, C. M. (2016). The Toronto hospital alertness test scale: Relationship to daytime sleepiness, fatigue, and symptoms of depression and anxiety. *Nature and science of sleep*, *8*, 41.

Shavers, V. L., Bakos, A., & Sheppard, V. B. (2010). Race, ethnicity, and pain among the US adult population. *Journal of Health Care for the Poor and Underserved*, *21*(1), 177-220.

Sherman, A. C., Simonton, S., Latif, U., Plante, T. G., & Anaissie, E. J. (2009). Changes in quality-of-life and psychosocial adjustment among multiple myeloma patients treated with high-dose melphalan and autologous stem cell transplantation. *Biology of Blood and Marrow Transplantation*, *15*(1), 12-20.

Singh, K., & Hodgson, D. (2011). How can the multi-disciplinary team meet the psychological needs of adolescents with cancer? A review of the literature. *Journal of Radiotherapy in Practice*, *10*(01), 55-64.

Smedley, B. D., Stith, A. Y., & Nelson, A. R. (Eds.). (2002). *Unequal treatment: Confronting racial and ethnic disparities in health care (full printed version)*. National Academies Press.

Smith, A. K., McCarthy, E. P., Paulk, E., Balboni, T. A., Maciejewski, P. K., Block, S. D., & Prigerson, H. G. (2008). Racial and ethnic differences in advance care planning among patients with cancer: impact of terminal illness acknowledgment, religiousness, and treatment preferences. *Journal of Clinical Oncology*, *26*(25), 4131-4137.

Smith, A. W., Bellizzi, K. M., Keegan, T. H. M., Zebrack, B., Chen, V. W., Neale, A. V., … Lynch, C. F. (2013). Health-related quality of life of adolescent and young adult patients with cancer in the United States: The adolescent and young adult health outcomes and patient experience study. *Journal of Clinical Oncology*, *31*(17), 2136–2145.

Smith, A. W., Seibel, N. L., Lewis, D. R., Albritton, K. H., Blair, D. F., Blanke, C. D., ... & Tricoli, J. V. (2016). Next steps for adolescent and young adult oncology workshop: an update on progress and recommendations for the future. *Cancer, 122, 988-999.*

Spelten, E. R., Sprangers, M. A., & Verbeek, J. H. (2002). Factors reported to influence the return to work of cancer survivors: a literature review. *Psycho-Oncology*, *11*(2), 124-131.

Spelten, E. R., Verbeek, J. H. A. M., Uitterhoeve, A. L. J., Ansink, A. C., Van Der Lelie, J., De Reijke, T. M., ... & Sprangers, M. A. G. (2003). Cancer, fatigue and the return of patients to work—a prospective cohort study. *European Journal of Cancer*, *39*(11), 1562-1567.

Standing, G. (2011). *The precariat: The new dangerous class*. A&C Black.

Stein, G. L., Supple, A. J., Huq, N., Dunbar, A. S., & Prinstein, M. J. (2016). A longitudinal examination of perceived discrimination and depressive symptoms in ethnic minority youth: The roles of attributional style, positive ethnic/racial affect, and emotional reactivity. *Developmental psychology*, *52*(2), 259.

Pryce, J., Munir, F., & Haslam, C. (2007). Cancer survivorship and work: symptoms, supervisor response, co-worker disclosure and work adjustment. *Journal of occupational rehabilitation*, *17*(1), 83-92.

Steinberg, L., & Morris, A. S. (2001). Adolescent development. *Journal of Cognitive Education and Psychology*, *2*(1), 55-87.

Stewart, D. E., Cheung, A. M., Duff, S., Wong, F., McQuestion, M., Cheng, T., ... & Bunston, T. (2001). Long-term breast cancer survivors: confidentiality, disclosure, effects on work and insurance. *Psycho‐Oncology*, *10*(3), 259-263.

Stewart, B., & Wild, C. P. (2016). World cancer report 2014. *World*.

Stokols D. Translating social ecological theory into guidelines for community health promotion. Am J Health Promotion 1996;10:282–98.

Swanberg, Jennifer E., Helen M. Nichols, Jungyai Ko, J. Kathleen Tracy, and Robin C. Vanderpool. "Managing cancer and employment: Decisions and strategies used by breast cancer survivors employed in low-wage jobs." *Journal of Psychosocial Oncology* 35, no. 2 (2017): 180-201.

Tai, E., Buchanan, N., Townsend, J., Fairley, T., Moore, A., & Richardson, L. C. (2012). Health status of adolescent and young adult cancer survivors. *Cancer*, *118*(19), 4884–4891.

Tajfel, H. E. (1978). *Differentiation between social groups: Studies in the social psychology of intergroup relations*. Academic Press.

Taylor, V. R. (2000). *Measuring healthy days: Population assessment of health-related quality of life*. US Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Division of Adult and Community Health.

Taylor, P. & Gao, G. (2014, June 5). Generation X: America's neglected 'middle child**.**' *Fact Tank.* Retrieved from http://www.pewresearch.org/fact-tank/2014/06/05/generation-x-americas-neglected-middle-child/

Tervalon, M., & Murray-Garcia, J. (1998). Cultural humility versus cultural competence: a critical distinction in defining physician training outcomes in multicultural education. *Journal of health care for the poor and underserved*, *9*(2), 117-125.

Thomas, D. M., Seymour, J. F., O'Brien, T., Sawyer, S. M., & Ashley, D. M. (2006). Adolescent and young adult cancer: a revolution in evolution?. *Internal medicine journal*, *36*(5), 302-307.

Thornes, R. (2002). *Palliative care for young people aged 13-24 years*. S. Elston (Ed.). Association for Children with Life-threatening or Terminal Conditions and their families.

Treadgold, C. L., & Kuperberg, A. (2010). Been there, done that, wrote the blog: the choices and challenges of supporting adolescents and young adults with cancer. *Journal of Clinical Oncology*, *28*(32), 4842–4849.

Treiber, F. A., Schramm, L., & Mabe, P. A. (1986). Children's knowledge and concerns towards a peer with cancer: A workshop intervention approach. *Child psychiatry and human development*, *16*(4), 249-260.

Vardy, J. (2009). Cognitive function in breast cancer survivors. In *Adjuvant Therapy for Breast Cancer* (pp. 387-419). Springer US.

Vogt, W. P., Gardner, D. C., & Haeffele, L. M. (2012). *When to use what research design*. Guilford Press.

Vygotsky, L. S. (1980). *Mind in society: The development of higher psychological processes*. Harvard university press.

Wefel, J. S., & Schagen, S. B. (2012). Chemotherapy-related cognitive dysfunction. *Current neurology and neuroscience reports*, *12*(3), 267-275.

Williams, B. R. (2004). Dying young, dying poor: a sociological examination of existential suffering among low-socioeconomic status patients. *Journal of palliative medicine*, *7*(1), 27-37.

Xavier, A. C., & Costa, L. J. (2015). Changes in the use of radiation therapy for early classical Hodgkin lymphoma in adolescents and young adults: implications for survival and second malignancies. *Leukemia & lymphoma*, *56*(8), 2339-2343.

Yang, Y. (2008). Social inequalities in happiness in the United States, 1972 to 2004: An age-period-cohort analysis. *American Sociological Review*, *73*(2), 204-226.

Zafar, S. Y., Peppercorn, J. M., Schrag, D., Taylor, D. H., Goetzinger, A. M., Zhong, X., & Abernethy, A. P. (2013). The financial toxicity of cancer treatment: a pilot study assessing out-of-pocket expenses and the insured cancer patient's experience. *The oncologist*, *18*(4), 381-390.

Zebrack, B. (2000). Cancer Survivors and Quality of Life: A Critical Review of the Literature. *Oncology Nursing Forum.* 27, 1395-1401.

Zebrack, B. J., Ganz, P. A., Bernaards, C. A., Petersen, L., & Abraham, L. (2006). Assessing the impact of cancer: development of a new instrument for long-term survivors. *Psycho-Oncology*, *15*(5), 407-421.

Zebrack, B., Hamilton, R., & Smith, A. W. (2009, October). Psychosocial outcomes and service use among young adults with cancer. In *Seminars in oncology* (Vol. 36, No. 5, pp. 468-477). WB Saunders.

Zebrack, B. J., Donohue, J. E., Gurney, J. G., Chesler, M. A., Bhatia, S., & Landier, W. (2010). Psychometric evaluation of the impact of cancer (IOC-CS) scale for young adult survivors of childhood cancer. *Quality of Life Research*, *19*(2), 207-218.

Zebrack, B. J. (2011). Psychological, social, and behavioral issues for young adults with cancer. *Cancer*, *117*(S10), 2289-2294.

Zebrack, B. J., Block, R., Hayes-Lattin, B., Embry, L., Aguilar, C., Meeske, K. A., ... & Cole, S. (2013). Psychosocial service use and unmet need among recently diagnosed adolescent and young adult cancer patients. *Cancer*, *119*(1), 201-214.

Zebrack, B., & Isaacson, S. (2012). Psychosocial care of adolescent and young adult patients with cancer and survivors. *Journal of Clinical Oncology*, *30*(11), 1221-1226.

Zebrack, B., Mathews-Bradshaw, B., & Siegel, S. (2010). Quality cancer care for adolescents and young adults: a position statement. *Journal of Clinical Oncology*, *28*(32), 4862-4867.