

ADOLESCENT AND YOUNG ADULT ONCOLOGY
PATIENTS AND THEIR CAREGIVERS

by

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Nearly 70,000 adolescents and young adults (AYA; ages 15-39) are diagnosed with cancer each year. Despite AYAs being identified in the late 1990s as a biopsychosocially distinct population from children and adults, they continue to experience stagnant survival rates and report complex unmet psychosocial needs. In order to explore the complexity of AYA patients' unmet psychosocial needs, two research articles were completed: (a) a systematic literature review examined which demographic variables are associated with disparities in incidence and mortality rates, access to care, and unmet supportive care needs among young adults with cancer, and (b) a descriptive cross-sectional study examined the interconnectedness of distress and coping among young adults with cancer and their caregivers. The systematic review revealed that some groups of AYA oncology patients, including non-White patients, those without insurance and those who live in neighborhoods with a lower socioeconomic status, experience additional disparities with regard to incidence and mortality rates, access to care, and unmet supportive care needs. The research study revealed that there was a mix of caregivers who provide AYA patients support including parents, spouses, friends, dating partners, and non-parent family members and that coping and distress are interconnected among AYA patients and their caregivers. Results from both articles form the basis for recommendations intended for researchers, healthcare

providers, and policy makers in their efforts to improve the biopsychosocial well-being of AYA oncology patients and their caregivers. Recommendations included the need for more dyadic and social network research designs, more clinical and research attention to the caregivers of AYAs, and increased training and education for healthcare providers who care for AYAs.

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PATIENTS AND THEIR CAREGIVERS

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DEDICATION

This dissertation is dedicated to the family of Vanessa Varela. While it has been several years since we had to say good-bye, it is my memories of Vanessa and your family that remind me every day why young adults with cancer and their families are unique. While this dissertation process has come to an end, I will forever remain an advocate for patients like Vanessa. She has always and will always be my inspiration.

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I would like to thank my family and friends for their support throughout my educational endeavors. I am so fortunate to have such wonderful parents, who have always supported my dream of getting a PhD. I would like to thank my mom, who has always pushed me to do my best and to never let anything stand in the way of my dreams.

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PREFACE

This dissertation includes six chapters that addresses some of the systemic and relational issues that adolescent and young adult (AYA) oncology patients face as they go through the cancer continuum from diagnosis to survivorship. My specific interest in young adult oncology grew out of a personal experience. At the age of 23, a close friend of mine was diagnosed with stage IV colorectal cancer. Despite intensive treatment, she passed away eight months after being diagnosed. Over the course of those eight months, I saw how the cancer impacted her relationship with her family. I saw the distress that every single member of her family went through and how helpless they felt as the oncology team mostly ignored them. It was soon after my friend passed that I began to read more about the experiences of other young adults with cancer.

Around this time, I was working at Oregon Health and Science University (OHSU), which was and still is recognized as one of the best cancer programs for young adults in the United States. Through a colleague, I was introduced to Dr. Rebecca Block, the director of the program. Dr. Block offered me a research internship. Through this internship, I came to recognize the complexity of the issues that young adults face and the need for those issues to be assessed at multiple levels.

As I was recognizing my passion for adolescent and young adult oncology, I started the master's program in Marriage, Couple and Family Therapy (MCFT) at Lewis and Clark College. I was drawn to this program for its emphasis on social justice; however, I struggled with the lack of attention to the intersection of biomedical and psychosocial health in my studies. My need to combine my passion for social justice and equality, with a whole-person approach to health led me to my doctoral studies in Medical Family Therapy (MedFT) at East Carolina University. The

MedFT program has a foundation in traditional couple and family therapy and applies the tenants of the biopsychosocial-spiritual framework (Engel, 1977, 1980; Watson, Wright, & Bell, 1996) to attend to whole-person care through research and clinical work (Hodgson, Lamson, Mendenhall, & Crane, 2014; McDaniel, Doherty, & Hepworth, 2014). I finally felt as if I had found my academic home.

As I started my studies at ECU, I could not let go of some of the stories that I had heard from some of the patients that I had met. Many of their stories focused on issues regarding access to care and feeling understood by their healthcare team. Their stories, along with my social justice training in my master's program, inspired the first article in this dissertation – a systematic review examining which sociodemographic variables are associated with disparities in incidence and mortality rates, access to care and unmet supportive care needs. As an advocate for young adults with cancer, I was disappointed by the magnitude of the disparities identified through the systematic review. The general AYA cancer population has stagnant survival rates as compared to pediatric and older adult populations and findings from the systematic review concluded there are some groups of AYA patients that have even more worse outcomes. This article ends with the call to action for researchers, clinicians, and policy makers to recognize these disparities and develop systemic interventions to address them.

The second article was inspired by the distress my friend's family experienced. While my friend went through treatment, I remember long conversations with her dad about how he was struggling to cope with his daughter's cancer and how difficult it was for him to watch her suffer. Often her family talked about how they felt invisible to the oncology healthcare team and how much that upset them. After seeing similar struggles in the dynamics among some of the clients I have seen in therapy, I began to do my own research on the topic. I found very little in the

literature about how the caregivers of young adults with cancer manage their distress. The literature about older patients suggested that distress and coping are interconnected among cancer patients and their caregivers (Gregorio et al., 2012; Kim & Given, 2008; Segrin, Badger, Dorros, Meek, & Lopez, 2007). Thus, I decided to move forward to learn more about whether distress and coping was also interrelated among young adults with cancer and their caregivers through a dyadic approach that includes patients and their caregivers in one study design. The findings from the second article indicate that AYA patients lean on a variety of caregivers including parents, partners, friends, spouses, other family members, and two even reported not having a caregiver. Beyond just identifying who the caregivers were, distress and coping was found to be interconnected among AYA patients and their caregivers. The interconnected nature may be highly influenced by relational dynamics among AYA patients and their caregivers; therefore, studying patients or caregivers as independent groups only tells parts of the story. Dyadic studies, while challenging due to additional recruitment barriers, additional costs, and more complex statistics, are essential to help understand phenomenon among the AYA population that remains unexplained, such as the stagnation in their survival rates (Bleyer, Choi, Fuller, Thomas, & Wang, 2009; Tai et al., 2012).

It is my hope that the findings of these two articles will encourage healthcare providers, researchers, and policy makers to extend their focus from just the patient and to consider the patient within the context of his or her relationships and the greater society. Very few life events occur in isolation, whether the event is a rite of passage (e.g., a wedding) or a mundane but necessary task (e.g., grocery shopping). As such, research that is done to investigate the care of patients without considering how going through treatment for cancer impacts the patient and

those around him or her is limited in its applicability. This dissertation explores the opportunity to better understand relationships between the AYA patient and care provider.

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CHAPTER ONE: INTRODUCTION

The prevalence of cancer among adolescents and young adults (AYA; ages 15-39) grows as nearly 70,000 are diagnosed with cancer each year in the United States (National Cancer Institute [NCI], 2012). The most common types of cancer for younger AYAs (ages 15 to 24) include leukemia, lymphoma, and testicular cancer, while among older AYAs (ages 25 to 39), cervical, colorectal, and breast cancers are more common (NCI, 2012). Despite AYAs being identified in the late 1990s as a biopsychosocially distinct population from children and adults (Bleyer, 2002), they experience stagnant survival rates as compared to treatment gains for pediatric and older adult cancer populations (Adolescent and Young Adult Oncology Progress Review Group [AYAO PRG], 2006; Bleyer, Choi, Fuller, Thomas, & Wang, 2009; Tai et al., 2012). With data from the NCI Surveillance, Epidemiology and End Results database for patients between 1973 and 2002, Bleyer and colleagues (2009) concluded that when compared to younger and older groups across the last 30 years, 15- to 39-year olds have the lowest conditional five-year survival improvement for all cancers, with those aged 20 to 29 having the least improvement in survival rates.

Several factors have been associated with the lack of improvement in survival rates for AYA oncology patients. These factors include limited knowledge about biomedical differences of AYA cancers, a lack of targeted biomedical interventions, limited participation in clinical trials, and limited psychosocial services that are specific to AYAs (AYAO PRG, 2006; Evan & Zeltzer, 2006; Haase & Phillips, 2004; Zebrack et al., 2013; Zebrack, Hamilton, & Smith, 2009). AYAs are physiologically and pharmacologically different than younger or older patients, which experts speculate may impact their susceptibility to and treatment of cancer (Bleyer et al., 2008). However, AYA patients' low rates of participation in clinical trials limited the availability of

tumor specimens needed for identifying biological differences and developing targeted interventions (Bleyer, Budd, & Montello, 2006; Bleyer et al., 2008). Many treatments administered to AYAs were originally developed for younger or older patients and treatment efficacy in AYAs, which may differ from younger or older patients, deserves further study (Bleyer, 2007). Additionally, because patients are typically divided into either pediatric or adult cancer settings, researchers have been limited in their ability to efficiently isolate biomedical and psychosocial data on those aged 15 to 39 (Bleyer et al., 2008).

The NCI and the National Comprehensive Cancer Network developed clinical and research recommendations aimed to address the survival disparity of AYA oncology patients (AYAO PRG, 2006; Coccia et al., 2012). In response to these recommendations, multiple AYA-specific programs opened and biomedical and psychosocial research with this population increased to understand influences of treatment decisions and address barriers to survivorship (Ferrari et al., 2010; Reed, Block, & Johnson, 2014). However, even with this growth, AYA patients reported a variety of unmet psychosocial needs (Dyson, Thompson, Palmer, Thomas, & Schofield, 2012; Keegan et al., 2012; Smith et al., 2013; Zebrack et al., 2013; Zebrack et al., 2014). As patients continue to report unmet psychosocial needs, it is time for researchers and healthcare providers to expand their viewpoint from the individual patient and begin to consider the cancer patient within the context of her or his relational and social contexts. Caregivers, such as parents, spouses, and friends, provide patients emotional, practical, financial and medical support, including providing transportation and accompaniment to medical appointments, coordination of multiple healthcare settings, administration of medications, assistance with activities of daily livings, housework and helping to manage patients' emotional distress (Girgis et al., 2013; Li et al., 2013; Romito et al., 2013; Yabroff & Kim, 2009) who provide meaningful

The purpose of this chapter is to: (a) provide an overview of AYA oncology patients and their caregivers, (b) present the theoretical foundation for this dissertation, (c) discuss the purpose of the dissertation study, and (d) provide an overview of the chapters included in this dissertation.

AYA Oncology Patients and Their Caregivers

As AYA patients face cancer, caregivers provide valuable practical, emotional, financial and medical support (Stenberg, Ruland, & Miaskowski, 2010; Woodgate, 2006). Having this support helps AYA manage their distress levels (Coyne, Wollin, & Creedy, 2012; Evan & Zeltzer, 2006; Grinyer, 2003); yet, little is known about how caregivers experience the distress of being a caregiver to an AYA patient. Researchers reported that distress among caregivers of adult oncology patients was related to type of care provided, the patient's symptoms, physical health and distress levels, the type of relationship, and caregiving burden (Applebaum & Breitbart, 2013; Dumont et al., 2006; Fujinami et al., 2014; Hodges, Humphris, & Macfarlane, 2005; Li et al., 2013; Northouse et al., 2012; Sharpe, Butow, Smith, McConnell, & Clarke, 2005; Stenberg, Cvancarova, Ekstedt, Olsson, & Ruland, 2014). Furthermore, there is evidence to suggest that distress is shared among patients and their caregivers (Gregorio et al., 2012; Juth et al., 2015; Kim & Given, 2008; Segrin, Badger, Dorros, Meek, & Lopez, 2007).

Distress that is shared among two individuals in response to a stressor is commonly referred to as dyadic distress (Bodenman, 1995, 2005). A characteristic that is dyadic in nature is best studied through a dyadic approach; an approach where both members of the dyad participate in the study (Kenny, Kashy, & Cook, 2006). In the adult oncology (>39) literature, higher levels of dyadic distress were associated with higher levels of unmet health and supportive care needs, presence of anxiety of depression, relationship dissatisfaction, lack of family support and caregiving burden (Baider, Goldzweig, Ever-Hadani, & Peretz, 2008; Baucom et al., 2012;

Milbury, Badr, Fossella, Pisters, & Carmack, 2013; Segrin & Badger, 2014). One research team studying AYA patients (ages 12 to 24), and their caregivers, examined the shared experience of stress (Juth, Silver, & Sender, 2015). Juth and colleagues (2015) reported that AYA patients and their caregivers shared similar levels of stress. However, the researchers did not consider the role of coping, relationship dynamics, or caregiver burden, which would provide valuable insight about how caregivers of AYA manage their roles and provide support to patients.

Most AYA research has focused on the individual patient experience with minimal research on the caregiver experience. Much of this research has ignored the relationship dynamics that influence distress among AYA patients and their caregivers. Taking a relational lens that looks at the patient and caregiver dyad provides valuable insight into relational factors that may be present. Beyond just the relational lens, valuable insight can also be gained from a systemic view that aims to additional barriers or disparities that AYA oncology patients face. However, before discussing the purpose of this dissertation study, it is important to understand the theoretical foundation of this dissertation.

Theoretical Foundation

Three theories were selected for this dissertation in conceptualizing and understanding the uniqueness of AYA patients and their caregivers. Prior to studying how distress and coping are interrelated among a AYA oncology patient-caregiver dyad, a systematic review was conducted to identify the disparities that AYA patients face with regard to incidence and mortality rates, access to care, and unmet supportive care needs. Intersectionality theory (Crenshaw, 1989, 1991, 1995) was selected as a framework for understanding these disparities (Chapter 2). Subsequent to a thorough review of the disparities uncovered with the AYA population, two additional theories, the developmental theory of emerging adulthood (Arnett,

2000, 2003), and the systemic transactional model (Bodenmann, 1995, 2005) provided a foundation for understanding the developmental challenges of AYAs and the interrelated nature of distress and coping among patients and their caregivers (Chapter 3). Together these three theories help to provide a more well-rounded theoretical view of what may be happening with the AYA population and why survival rates are stagnated (AYAO PRG, 2006; Nass & Patlak, 2013).

Intersectionality Theory

Proponents of intersectionality theory (IT) posited that patients, families, and communities' experiences are shaped by the interaction of multiple sociodemographic factors (e.g., age, gender, race/ethnicity, sexual orientation) and these interactions also intersect with individuals' social experiences (Crenshaw, 1989, 1991, 1995). Crenshaw and others examined how one's experience in any setting is shaped by interlocking system of power, privilege, and oppression (Bowleg, 2012; Collins, 1991; Crenshaw, 1989, 1991, 1995; Davis, 2008) and how the system may contribute to disparities faced by some groups in the population. These tenants of IT support its use as a systemic lens through which to consider some of the larger systems challenges and barriers that AYA oncology patients may face.

Previous researchers reported that some AYA patients face additional survival rate disparities by race/ethnicity (Howlader et al., 2014; NCI, 2012), socioeconomic status (Kent, Sender, Largent, & Anton-Culver, 2009; Smith, Ziogas, & Anton-Culver, 2012), gender (Smith, Ziogas, & Anton-Culver, 2013), and sexual orientation (Machalek et al., 2012; Tracy, Schluterman, & Greenberg, 2013). With evidence of these disparities, intersectionality theory was chosen to guide the systematic review (Chapter 2) in order to further understand the association between sociodemographic variables and disparities in incidence and mortality,

access to care, and unmet supportive care needs among AYA oncology patients. Understanding these disparities is vital to recognizing that some of patients' barriers and challenges to survivorship are beyond just their individual responses to biomedical treatments and psychosocial interventions. This information is necessary for understanding the complexity and diversity of the AYA oncology patient population.

Emerging Adulthood

While intersectionality theory provides a framework for understanding disparities faced across the AYA patient population, the developmental theory of emerging adulthood (Arnett, 2000, 2003) provides insight to the developmental tasks and challenges typical of this age range. Arnett (2000, 2003) described emerging adulthood as a developmental stage that occurs between the ages of 18 and 30 and is remarkably different than adolescence and adulthood. As the most transitory phase of life, emerging adults are in the midst of navigating and negotiating their relationships with their families of origins while also developing other systems of support (Arnett, 2007). The transition through emerging adulthood and into adulthood is naturally challenging and additional stressors, such as cancer, may overwhelm individuals' ability to manage multiple stressor. For this reason, the developmental theory of emerging adulthood (Arnett, 2000, 2003) was chosen as the theoretical foundation for understanding why AYAs are unique developmentally and sets the foundation for why particular attention to their psychosocial needs is necessary. The developmental theory of emerging adulthood (Arnett, 2000, 2003) is paired with the systemic transactional model (Bodenmann, 1995, 2005) for understanding how distress is interrelated among AYA oncology patients and their caregivers.

Systemic Transactional Model

The systemic transactional model (STM) posits that distress and coping are interrelated among individuals in a close relationship when faced with a shared stressor (Bodenmann, 1995, 2005). Cancer is an example of a shared or dyadic stressor because it has the potential to directly and indirectly impact the patient and her or his caregiver. According to STM theorists, when a dyad, such as a patient and his or her caregiver, is faced with a shared stressor, partners cope both individually and jointly (Bodenmann, 1995, 2005). Several researchers found strained coping, lower relationship quality, and increased distress levels reported among heterosexual patient-spousal dyads facing cancer (e.g., Badr, Carmack, Kashy, Cristofanilli, & Revenson, 2010; Feldman & Broussard, 2006; Manne et al., 2004; Traa, de Vries, Bodenmann, & Den Oudsten, 2015). Intersectionality theory (Crenshaw, 1989, 1991, 1995), the developmental theory of emerging adulthood (Arnett, 2000, 2003) and STM (Bodenmann, 1995, 2005) together set the foundation for understanding the heterogeneity of the AYA patient population, normal developmental tasks and how the experience of distress is shared with their caregivers.

Purpose

As AYAs continue to experience stagnant survival rates (Bleyer et al., 2009; Tai et al., 2012) and complex psychosocial needs (e.g., Zebrack et al., 2013), this is an opportune time for researchers and healthcare providers to broaden their perspective and consider AYA patients from a more comprehensive approach that attends to the relational and social context. These efforts are necessary in order to understand the complexities of the issues contributing to the stagnant survival rates. Contributors to the adult oncology literature suggested that distress levels between patients and their caregivers are interrelated (Gregorio et al., 2012; Juth et al., 2015; Kim & Given, 2008; Segrin et al., 2007). Through a dyadic analysis, that examined

simultaneously patients' and their caregivers stress, Juth and colleagues (2015) concluded that AYA oncology patients and their caregivers do indeed experience similar levels of stress; however, the role of relationship quality, coping strategies and caregiver burden among AYA patients and their caregivers was not examined. Dyadic research, that includes patients and an important member of their support system, such as a caregiver, is necessary for developing programs and interventions better targeted at meeting patients' and their caregivers' needs. Continuing to not acknowledge the shared experience of cancer on AYAs and their caregivers will likely result in ongoing reports of unmet psychosocial needs and heightened distress among AYA patient-caregiver dyads.

Conclusion

The ensuing chapters will expand and enhance researchers' and healthcare providers' understanding of the challenges faced by AYA oncology patients and their caregivers. This dissertation begins with an emphasis on understanding the disparities faced by AYA oncology patients, as guided by intersectionality theory. Understanding the disparities experienced by portions of the AYA oncology patient population provides insight into some of the potential sources of stress that patients may experience as they are diagnosed with and undergo treatment for cancer. Then the dissertation will shift toward understanding the experience of distress, relationship quality, and coping among AYA oncology patients and their caregivers.

The second chapter of this dissertation is the first article of this dissertation. It is a systematic literature review guided by intersectionality theory (Crenshaw, 1989, 1991, 1995) and aims to address the following research question: "What sociodemographic factors are associated with disparities in incidence and mortality rates, access to care, and unmet needs among young adults with cancer?" Findings from 42 articles that met the inclusion criteria provide evidence

that there are additional disparities faced by some AYA oncology patients, with regard to incidence and mortality rates, access to care, and unmet supportive care needs. Articles included in the systematic review included results that were reported as being statistically significant or stated as being important by the author. Examples of recommendations from the systematic review include expanding national cancer registries to include additional sociodemographic information, (i.e., nation of origin, sexual orientation, marital status) and increasing research at the community and local level to understand how disparities vary across communities.

The third chapter included in this dissertation provides a thorough review of the empirical literature about the role of distress and coping among: (a) AYA oncology patients, (b) caregivers of cancer patients, and (c) cancer patient-caregiver dyads, as guided by the developmental theory of emerging adulthood (Arnett, 2000, 2003) and the systemic transactional model (Bodenmann, 1995, 2005). This literature review aims to provide insight about how distress, relationship quality, coping, and caregiver burden are associated among oncology patients and their caregivers. While researchers have examined these factors among adult oncology patients and their caregivers, no known researchers examined the interaction of these factors with AYA oncology patients and their caregivers, despite evidence that they share similar levels of distress (Juth et al., 2015).

The fourth chapter of this dissertation includes a description of the methodology used to expand knowledge about how distress and coping are experienced among AYA oncology patients and their caregivers. This methodology is grounded in the theory of emerging adulthood (Arnett, 2000, 2003) and systemic transactional model (Bodenmann, 1995, 2005). A cross-sectional quantitative survey design was utilized to help fill the gaps in the literature by answering the following research questions: (a) Who are the caregivers of young adults with

cancer and how does the type of caregiver (e.g., parent, spouse, sibling, friend) vary across sociodemographic variables? (b) Are patients who participated in the dyadic portion different from those patients who did not participate in the dyadic portion? (c) Are caregivers who participated in the dyadic portion different from those caregivers who did not participate in the dyadic portion? (d) What is the association between distress, coping strategies, and relationship satisfaction among a sample of AYAs with cancer? (e) What is the association between distress, coping strategies, relationship satisfaction and caregiver burden among a sample of caregivers of young adults with cancer? and (f) What is the association between dyadic distress and coping strategies among a sample of matched AYA oncology patients and their caregivers?

The fifth chapter and second article of this dissertation aimed to address the gaps identified through the literature review presented in chapter three by completing the methodology presented in chapter four. Findings from the second article provided preliminary evidence there is a mix of caregivers including parents, dating partners, spouses and non-parent family who provide support to AYA patients and that distress and coping strategies are interconnected among AYA patients and their caregivers. As well, findings from this study suggest those caregivers who did not participate in the study with their patient may actually be more distressed than those caregivers who participated in the dyadic portion of the study. Recommendations from this study included the need for researchers and clinicians to attend to relational dynamics among patients and their caregivers in efforts to reduce distress.

Finally, the sixth chapter of this dissertation includes a discussion of the findings from both articles, and implications for researchers, clinicians and policy makers. Recommendations from this dissertation included the need for a more systemic and relational approach to research and clinical care for AYA oncology patients. Utilizing a more systemic and relational approach

will provide researchers and healthcare providers understand AYAs and the experiences they have as they are diagnosed with and undergo treatment for cancer. This will help AYA program administrators and clinicians develop targeted interventions aimed at meeting the unique psychosocial needs of this patient and caregiver population.

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CHAPTER TWO: HEALTHCARE DISPARITIES FACED BY ADOLESCENT AND YOUNG ADULT ONCOLOGY PATIENTS: A SYSTEMATIC REVIEW

Nearly 70,000 adolescents and young adults (AYA; ages 15-39) are diagnosed with cancer each year (National Cancer Institute [NCI], 2012). This equates to approximately 2% of all invasive cancers (Bleyer, O’Leary, Barr, & Ries, 2006), which is four times greater than the rate of cancer among individuals under the age of 15 (Bleyer & Barr, 2009). Among individuals aged 20 to 39, cancer is the second leading cause of death (Bleyer & Barr, 2009). The most common types of cancer for younger AYAs (ages 15 to 24) include leukemia, lymphoma, and testicular cancer, while among older AYAs (ages 25 to 39), it is cervical, colorectal, and breast cancers (NCI, 2012). Some cancers, such as Hodgkin lymphoma, testicular cancer, bone sarcomas, and Kaposi sarcoma peak in incidence during the 15 to 39 age range (Bleyer et al., 2008). While AYAs were initially identified as a unique population in the late 1990s (Adolescent and Young Adult Oncology Progress Review Group [AYAO PRG], 2006; Bleyer, 2002), these patients continue to experience stagnant survival rates as compared to pediatric and older adult cancer populations (Bleyer, Choi, Fuller, Thomas, & Wang, 2009; Bleyer et al., 2006; Tai et al., 2012). This systematic review aims to: (a) identify sociodemographic variables associated with health disparities in incidence and mortality rates, access to care and unmet supportive care needs experienced by AYA oncology patients and (b) introduce intersectionality theory (Crenshaw, 1991, 1995) in the application of addressing these disparities.

Disparities Among AYA Oncology Patients

The disparities and lack of improvement in survival rates faced by AYA patients have captured national attention (AYAO PRG, 2006) and clinical guidelines have been developed for working with this patient population (Coccia et al., 2012). There continues to be a paucity of

knowledge about biological differences of AYA cancers from those of other age groups, limited participation in clinical trials, a lack of targeted biomedical interventions, and limited psychosocial services that are specific to AYAs (AYAO PRG, 2006; Bleyer et al., 2008; Evan & Zeltzer, 2006; Haase & Phillips, 2004; Zebrack et al., 2013; Zebrack, Hamilton, & Smith, 2009). Researchers have uncovered that AYAs are physiologically and pharmacologically different than younger or older patients, which may impact their susceptibility to and treatment of cancer (Bleyer et al., 2008). Some biological differences have been thus far identified for breast cancer, colorectal cancer, acute lymphoblastic leukemia, non-Hodgkin's lymphoma, Ewing sarcoma, gastrointestinal stromal tumor, liver cancer, melanoma, and some other less frequently occurring cancers (Bleyer et al., 2008). However, AYA patients' low rates of participation in clinical trials limit the availability of tumor specimens needed for identifying biological differences and developing targeted interventions (Bleyer et al., 2008; Bleyer, Budd, & Montello, 2006). Many treatments administered to AYAs were originally developed for younger or older patients rather than specifically for AYAs (Bleyer, 2007). Additionally, because patients are typically divided into either pediatric or adult cancer settings, researchers are limited in their ability to isolate biomedical and psychosocial data on those aged 15 to 39 which is necessary for developing targeted interventions (e.g., Bleyer et al., 2008).

Research with AYA patients and AYA-specific programs within cancer centers has increased over the last ten years (Reed, Block, & Johnson, 2014). With the growth of the field, it is time that researchers and policy makers attend to the disparities experienced among patients within this population, not just as compared to other populations. NCI defines cancer healthcare disparities as “adverse differences in cancer incidence (new cases), cancer prevalence (all existing cases), cancer death (mortality), cancer survivorship, and burden of cancer or related

health conditions that exist among specific population groups in the United States.” (NCI, 2008). This systematic review aimed to identify sociodemographic variables associated with differences in incidence, prevalence and mortality rates, access to care, and unmet supportive care needs. Incidence is defined as the number of newly diagnosed cases of cancer during a certain period of time (NCI, n.d.). Prevalence is defined as the number of people who have a cancer diagnosis at a certain point in time (NCI, n.d.). Mortality is defined as the number of deaths during a certain time period (NCI, n.d.). Access to health care has a broader definition and is best viewed as "the timely use of personal health services to achieve the best health outcomes" (Institute of Medicine [IOM], 1993). This includes being able to assess the healthcare system and receiving care that meets the needs of patients (Agency for Healthcare Research and Quality, 2014), which includes access to timely screening and treatment. Unmet supportive care needs as defined differently by each researcher and generally include informational, practical and emotional needs.

Some AYA patients face survival rate disparities by race/ethnicity (Howlander et al., 2014; NCI, 2012), socioeconomic status (Kent, Sender, Largent, & Anton-Culver, 2009; Smith, Ziogas, & Anton-Culver, 2012), gender (Smith, Ziogas, & Anton-Culver, 2013), and sexual orientation (Machalek et al., 2012; Tracy, Schluterman, & Greenberg, 2013). Sociodemographic variables are also associated with differences in incidence rates (e.g., Bleyer, 2011; Robbins, Lerro, & Barr, 2014), access to care (e.g., Aizer et al., 2014; Kirchoff, Lyles, Fluchel, Wright, & Leisenring, 2012) and unmet supportive care needs (e.g., Keegan et al., 2012; Zebrack et al., 2013). Disparities in incidence and mortality rates also include differences in what stage AYAs are diagnosed with cancer. Some AYAs are at a higher risk for being diagnosed with a regional or distant stage of cancer, which is associated with fewer treatment options and poorer outcomes as compared to those diagnosed with a local stage cancer (Liu et al., 2013; Reis et al., 2007).

These disparities among AYA patients further ostracize an already marginalized patient population. A social justice-focused approach, such as intersectionality theory (Crenshaw, 1989, 1991, 1995), provides a framework for considering these disparities and provides factors to consider in the development of interventions targeted at addressing these disparities.

Intersectionality Theory

Intersectionality theory (IT) is a framework that supports examining how patients', families', and communities' experiences are shaped by the intersection of multiple social locations or sociodemographic factors (e.g., age, gender, race/ethnicity, sexual orientation; Crenshaw, 1989, 1991, 1995). Intersectionality theory originated from the work of African American feminists and critical race theorists who longed to shift from looking at single social locations toward considering the interactions between different social locations and how these different social locations intersect with multiple micro and macro levels of the individual's experience (Bowleg, 2012; Cole, 2009; Collins, 1991; Crenshaw, 1989, 1991, 1995). This includes examining how the experience is shaped by interlocking systems of power, privilege, and oppression (Bowleg, 2012; Collins, 1991; Crenshaw, 1991, 1995).

With regard to the application of IT to research, Cole (2009) proposes a consideration be made about: (a) who is included in the sample, (b) what role inequality plays, and (c) the similarities in the challenges faced by the sample. With regard to sample composition, AYAs are a unique patient population in comparison to their younger and older counterparts (e.g., AYAO PRG, 2006); however, there is also significant heterogeneity within the group that needs to be considered. The complexities of these patients' sociodemographic variables need to be considered as they intersect with disparities in incidence and mortality (e.g., Bleyer, 2011; Robbins et al., 2014), access to care (e.g., Aizer et al., 2014; Kirchoff et al., 2012) and having

their supportive care needs met (e.g., Keegan et al., 2012; Zebrack et al., 2013). Patients' lived experiences cannot be accurately captured if only one sociodemographic variable (e.g., age, race/ethnicity, gender, sexual orientation) is attended to, nor can the experience be explained by adding them together (Bowleg, 2012; Collins, 1995; Cole, 2009; Crenshaw, 1989, 1991; Davis, 2008). Rather, it is important to consider the sample for the heterogeneity that it contains.

In addition to examining the social locations of samples, researchers should consider the role of inequality that AYA participants may experience within the context of the research setting (Cole, 2009). Sociodemographic variables are not just individual characteristics, but are social processes that are influenced by a history of privilege and marginalization (Cole, 2009; Crenshaw, 1989). The larger social system shapes privilege and marginalization associated with age, race, gender, sexual orientation and many other aspects of patient's identity, to produce the lived experience (Bowleg, 2012). Patients carry this history with them to each new setting. Researchers failing to consider this may reinforce marginalization through their research design.

Finally, Cole (2009) encouraged researchers to consider commonalities in the challenges faced by populations from various intersecting social locations. Commonalities, such as lack of access to care, are experienced across more than one social location (e.g., race, gender or SES), thus interventions should not just target one social location but should address the commonality experienced across social locations. The experiences of marginalized communities are complex but there are commonalities that can be identified by prioritizing them and understanding how their experiences are similar or different from others.

The application of intersectionality theory, as a guiding framework for understanding disparities in cancer has been applied to research with lung cancer patients (Williams et al., 2012) and with regard to cervical cancer screenings (Agénor, Krieger, Austin, Haneuse, &

Gottlieb, 2014). In the case of lung cancer, mortality risk did not differ just by a single social location, or race, but by the intersection of gender, education level, and race (Williams et al., 2012). Black men had a higher risk of lung cancer mortality than White men at higher levels of education, but had nearly equal rates of mortality at the two lowest education levels (Williams et al., 2012). This intersecting pattern was different for women. Black women had lower lung cancer mortality risks than White women at the lowest levels of education, nearly equivalent risk in the middle categories and experienced increased risk at the highest level of education (Williams et al., 2012). This example highlights the intersecting effects of race, education, and gender and its impact on lung cancer mortality risk. Additional research is needed in order to better understand these intersecting effects. Failing to incorporate any one of these social locations would have resulted in inaccurate findings, which can greatly impact local and national interventions.

Cervical cancer screening rates have also been investigated through an intersectionality lens by Agénor and colleagues (2014). Agénor and colleagues reported over cervical cancer screenings were reported for White women who only had female sexual partners as compared to White women who had male sexual partners. Rates were even lower for Black women who had female sexual partners, however, this association did not hold for Hispanic women (Agénor et al., 2014). Furthermore, and important to note, health insurance status, receiving contraception and sexual transmitted infection services appeared to at least partially explain the relationship between sexual preference among White, Hispanic, and Black women (Agénor et al., 2014). This example illustrates the intersecting effects of sexual orientation, race, and insurance status, while also considering the impact of contraception and STI services on cervical cancer screenings.

The use of intersectionality theory in these two examples to consider the interaction of sociodemographic variables (Agénor et al., 2014; Williams et al., 2012) demonstrates the importance of moving away from addressing disparities by just one sociodemographic variable, such as race, but rather it encourages researchers to consider individuals and communities in their entirety (Bowleg, 2012; Cole, 2009). Using this lens encourages researchers to better understand the patient population as a whole, taking all of their sociodemographic variables into account (Bowleg, 2012; Cole, 2009).

The purpose of this systematic review is to provide a better understanding of these complexities by considering the sociodemographics of the sample and the inequalities experienced across the sample (Cole, 2009). Specifically, the aims of this systematic review were to: (a) conduct a systematic review of peer-reviewed empirical articles on differences associated with sociodemographic variables in incidence and mortality rates, access to care, and unmet needs among cancer patients aged 15 to 40 (b) highlight the gaps in the existing literature, and (c) provide recommendations for improving disparities through the use of intersectionality theory (Crenshaw, 1989, 1991, 1995). The primary research question that guided this systematic review was, “What sociodemographic factors are associated with disparities among young adults with cancer? Particularly, what sociodemographic factors are associated with disparities in incidence and mortality rates, access to care, and unmet needs among young adults with cancer?” This systematic review is a step towards identifying the disparities faced by this patient population. Identification of these factors is instrumental in the development of programs targeted for cancer patients of diverse backgrounds aged 15 to 40.

Method

This systematic review was completed using Cooper's (2010) seven-step model and the assistance of a second reviewer. The second reviewer was a master's student with previous experience with systematic reviews. The first step was to formulate the problem (Cooper, 2010), which as mentioned above was to identify sociodemographic variables associated with disparities faced by AYA oncology patients. The second step required searching the literature (Cooper, 2010), which was completed using CINAHL via EBSCO, PsycINFO via EBSCO, and Medline via PubMed (see Table 1). Synonymous subject headings and key terms were identified and used across the databases. In cases where subject headings did not match across databases, and an equivalent could not be identified, the term was used as a keyword (Table 2). Step 2 was completed with consultation from a librarian who is experienced with systematic reviews, the chosen databases and the search terms. To ensure that the search terms were applied consistently across databases, a second reviewer completed the same searches in the three databases. The first and second reviewer reported the same number of identified articles for all of the search terms. This search yielded a total 2,466 articles.

In the third step, the first author reviewed titles and abstracts of those articles identified in step two in order to gather information from the studies (Cooper, 2010). The following inclusion criteria were applied: (a) the study sample included cancer patients or survivors, or patients who received cancer screening or cancer related services, (b) the sample was collected in the United States, (c) the sample included participants aged 15 to 40, (d) separate results are reported for individuals 15 to 40, (e) incidence or mortality rates, access to care (including cancer screening, delayed treatment, cancer staging), or unmet health and supportive care needs were reported as outcomes, (f) data collection included at least two sociodemographic variables (e.g., age, gender,

race, ethnicity, socioeconomic status, education level, insurance status, urban/rural location), (g) included empirical research using a qualitative or quantitative methodology, (h) peer-reviewed article, and (i) published in English in the last ten years. Studies completed outside of the United States were excluded. This review's primary focus was to understand the disparities among AYA oncology patients in the United States in order to provide research and policy recommendations.

A total of 1,303 unique articles were identified once duplicates were removed (Cooper, 2010). Application of the inclusion criteria to the titles and abstracts resulted in 131 articles for full review. Application of the inclusion criteria by the first author and second reviewer to the 131 full articles resulted in 32 final articles to be included in this systematic review. Initially, the first author identified 30 articles and the second reviewer identified 46 articles, but through deliberation, a total of 32 articles were included in the systematic review. Deliberation included meeting together in person and jointly applying the criteria to the articles in questions in order to determine whether the article met the inclusion criteria. The reference lists from these articles were also reviewed and 10 additional articles were identified. These articles might have been missed in the initial systematic review due to which search terms were used or how search terms are applied to articles when they are filed. In total, 42 unique articles were included in this review. A diagram of the full process by which studies were selected for inclusion is provided in Figure 1.

To evaluate the quality of the studies for the fourth step, the following assessment criteria were applied: (a) objectives of hypotheses were clearly stated (DuRant, 1994; von Elm et al., 2007), (b) use of a defined sample that included a description of inclusion and exclusion criteria (Sanderson et al., 2007; von Elm et al., 2007), (c) information provided about non-respondents (DuRant, 1994; von Elm et al., 2007), (d) all variables were clearly defined (Sanderson et al.,

2007; von Elm et al., 2007), (e) statistical methods appropriate and clearly described, with control for confounding variables (DuRant, 1994; von Elm et al., 2007), (f) researchers considered the interaction of sociodemographic variables (Cole, 2009), (g) acknowledgement of potential sources of bias (Sanderson, Tatt, & Higgins, 2007; von Elm et al., 2007), and (h) source of funding was reported (Sanderson et al., 2007; von Elm et al., 2007). Both the first author and the second reviewer assessed all 42 articles and had 82% inter-rater reliability. Initial discrepancies were mostly related to interpreting the articles' statistics and information about non-respondents. Discrepancies were jointly reviewed in person by the first author and the master's student. Through conversation, the first author and the master's student re-applied each quality assessment criterion until a joint decision was made about whether the criteria was met or not. Results from the application of these criteria to the articles are provided in Table 3. In the fifth step, the analysis and integration of outcomes was completed (Cooper, 2010), which are provided in Tables 3 to 5. In the sixth and seventh steps, the evidence was interpreted and the results are presented (Cooper, 2010) in the proceeding section.

Results

The articles selected for this review explored the relationship between sociodemographic variables (e.g., age, gender, race/ethnicity, socioeconomic status, marital status) and disparities among adolescents and young adults with cancer. The results are divided into three themes of studies that investigated: (a) incidence and mortality, (b) access to care, and (c) unmet health and supportive care needs. Within the incidence and mortality, and unmet needs categories, studies are further divided by individual sociodemographic variables (e.g., age, gender, race/ethnicity) and combined sociodemographic variables (e.g., age and race/ethnicity), where applicable. Combined sociodemographic variables were reported by differences between age groups, rather

than reporting results for the entire 15 to 40 age range. The access to care category is further divided into subcategories by type of access issue (e.g., insurance, screening, treatment modalities)

A total of 42 articles met the inclusion criteria for this study, with some falling into more than one of the three themes. Three themes of disparities that were identified by the first author, and confirmed by the second reviewer, are as follows: (a) incidence, prevalence, and mortality, (b) access to care, and (c) unmet supportive care needs. In the following text, bracketed numbers refer to specific studies as indicated in Table 3. The corresponding numbers, as indicated in Table 3, are also included in Tables 4 – 6 for easy reference. Twenty-four studies reported on sociodemographic variables associated with incidence and mortality [1, 3, 4, 6 - 11, 13, 15 – 17, 20 - 22, 24, 26, 27, 29, 30, 34 - 37], 17 studies reported on sociodemographic variables associated with access to care [1, 2, 5, 10, 12, 13, 19, 22, 23, 25, 28, 30, 31, 32, 33, 34, 38], and five studies reported on sociodemographic variables associated with unmet supportive care needs [19, 39 – 42] (see Tables 4-6).

All of the studies met at least half of the quality assessment criteria (Table 2). All of the studies clearly presented the objective, described the inclusion and exclusion criteria, and defined all of the variables. Information about non-respondents was the least met criterion ($n = 12$), followed by the presence of the interaction of multiple sociodemographic variables ($n = 21$). Some studies included all ages with separate analyses completed for some part of the 15 to 40 age range [2, 3, 5 – 8, 13 - 17, 21, 26, 27, 29, 35, 36, 38], while other studies were only limited to participants within the 15 to 40 age range [1, 4, 9 - 12, 18 – 20, 22 - 25, 28, 30 - 34, 37, 39 – 43]. The results of this review are categorized across three themes: (a) incidence and mortality, (b) access to care, and (c) unmet supportive care needs.

Theme 1: Incidence, Prevalence, and Mortality

Twenty-four studies included in this review reported on incidence and mortality rates, as well as provided incidence information about cancers diagnosed at different stages. Nearly all of these studies reported incidence and mortality rates among AYA with data from state and national epidemiological datasets including the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program ($n = 15$) [1, 3, 4, 7, 9, 13, 15, 16, 24, 26, 29, 35 – 37], the National Cancer Database ($n = 3$) [7, 8, 30], North American Association of Central Cancer Registries ($n = 1$) [17], National Program of Cancer Registries ($n = 2$) [36, 37], the California Cancer Registry ($n = 4$) [11, 20, 21, 34], and the North Carolina Cancer Registry ($n = 1$) [6]. One study used data from the Behavioral Risk Factor Surveillance System (BRFSS) [22]. National registries provide valuable information about incidence and mortality; however, misclassification and incomplete reporting, as well as limited follow up data, are commonly reported concerns [15, 34, 37]. As seen below, national registries do not capture all of patients' sociodemographic variables and some studies reviewed only considered age, race, and/or gender [3, 4, 6, 7, 9, 13, 15 – 17, 21, 26, 27, 35 - 37]. Cancer stage at diagnosis was most often reported as a local, regional, or distant stage diagnosis [4, 24, 30, 37]. Summaries about articles that reported incidence, prevalence, and mortality information are provided in Table 4.

Age. Six studies included in this review investigated age differences associated with cancer incidence and mortality [6, 13, 21, 26, 37]. This included results for testicular [13, 26], melanoma [37] and leukemia [21].

Researchers across several studies reported that incidence for testicular [13, 26], cervical cancer [6], and melanoma cancers [37] increased from 15 to 39 years of age. The highest risk for seminoma testicular cancer was reported among males aged 35 to 39 [26]. The lowest risk for

melanoma [37] and testicular cancer [13, 26] was reported among patients between the ages of 15 and 19. Mortality from leukemia also increased from age 15 to 39 [21]. The highest incidence of melanoma was reported for patients aged 35-39 [37]. Women aged 30 to 39 had a higher incidence of and mortality from cervical cancer as compared to women aged 19 to 29 [6]. Additional studies are needed to understand how age is associated with cancer staging and tumor characteristics across a variety of cancers. Additional age differences are discussed with the intersection of race/ethnicity below.

Race/ethnicity. Eleven studies included in this review investigated how race and/or ethnicity differences are associated with cancer incidence and mortality rates. The included studies looked at rates for breast cancer [3, 7, 17, 24], colon and rectal cancers [27], nasopharyngeal carcinoma [29], non-Hodgkin's lymphoma [20], testicular cancer [4], melanoma [37], extracranial solid tumors [16], and staging for all cancers [30].

In the 18 to 39 age range, higher breast cancer incidence rates were reported for Black women as compared to White women [24]. Similar findings were reported for the 20 to 39 age range [17]. As well, researchers reported a higher percentage of cases in the NCDB and SEER databases of Black women aged 20 to 29 as compared to White women [7]. Breast cancer incidence rates were lower for American Indian/Alaskan Native (AI/AN) and Asian/Pacific Islander women (API) as compared to White women and Black women for the 25 to 39 age range [3, 17]. Higher rates of colon and rectal cancers were reported for Black men and women as compared to White men and women for those aged 30 to 39 [27]. Among patients with nasopharyngeal carcinoma aged 20 to 29, incidence rates were highest among Asian, followed by Black and then White patients [29].

The incidence of localized breast cancer tumors was highest among Asian women, as compared to White, Black, and Hispanic women [24]. However, Black women were most likely to be diagnosed with distant breast cancer disease and have an ER-positive tumor [24]. Asian women were most likely to have an ER-positive tumor [24]. Asian women with breast cancer had the highest 5-year overall survival rates as compared to White, Black, and Hispanic women; whereas, Black and API women with breast cancer had the lowest [24]. Studies that examined breast cancer incidence and mortality among males were not identified through this review.

Black and Hispanic patients in the 15-39 age range were reported to have lower rates of survival from non-Hodgkin's lymphoma than White patients [20]. Among 15 to 19 year olds, Black males had the lowest survival probability from extracranial solid tumors as compared to White, AI/AN and API patients [16]. Annual percentage change for the incidence for seminoma and non-seminoma testicular cancer subtypes was higher for Hispanic White males as compared to non-Hispanic White males [4]. This effect was reported to occur for all stages of the disease (e.g., local, regional and distant).

In contrast, White males and females experienced higher rates of melanoma, followed by AI/AN, Hispanic, API and then Black males and females [37]. Regional and distant stage melanomas were more common among Hispanic males and females as compared to White males and females [37]. For all cancers, Black, Hispanic and API patients were more likely to be diagnosed with a distant stage cancer as compared to White patients [37]. The highest proportion of distant staged cancers was among Black patients [37]. While all of the studies included in this section included Black and White samples, not all of the studies included AI/AN, API and Hispanic patients. This is likely due to a smaller number of AI/AN, API and Hispanic patients in the registries. However, simply excluding them from analyses fails to provide valuable

information about their incidence and mortality rates. One way to address this may be to use matched samples, in order to have an equal number of patients of each racial or ethnic group. Future researchers and registry coordinators need to consider the complexity of race, as rates of multi-racial identities continue to increase in the United States (Alex-Assensoh, & Hanks, 2000; Blendon et al., 2007; Loretta, Winters, & Herman, 2003).

Combination of age and race/ethnicity. While many researchers examined overall differences by race/ethnicity across the entire age range, six studies also included differences in incidence and mortality combined for age and race/ethnicity. The cancers identified through the systematic review that included such results included breast [17, 35], testicular cancer [26, 36] and advanced stage Hodgkin's lymphoma [34]. Age and racial/ethnicity differences in incidence and mortality are presented below by cancer type.

Breast Cancer. Three studies reported age and race/ethnicity differences among women with breast cancer. Among women aged 20 to 24, higher incidence rates were observed among Hispanic women as compared to non-Hispanic women [17]. Among all age groups from 25 to 39, a crossover was observed and incidence rates were higher among non-Hispanic women as compared to Hispanic women [17].

Changes in yearly incidence rates also appeared to differ by age among White and Black women [35]. Among women aged 20 to 29, the change in breast cancer incidence rate per year was higher among Black women as compared to White women [35]. Among women aged 30 to 39, the change in breast cancer incidence rate per year was higher among White women as compared to Black women [35]. Examining crossover effects is important for understanding how breast cancer incidence and mortality is associated with age and race; however, these studies did

not include a wide variety of races or ethnic groups, such as API or AI/AN. The studies included here only included females.

Testicular cancer. Two studies reported about age and race/ethnicity differences among men with testicular cancer [26, 36]. Peak incidence rates of seminomas varied across age for different races/ethnicities [36]. Seminoma incidence rates peaked in the 20 to 24 age range for AI/AN men, in the 30 to 34 age range for Hispanic and API men, in the 30 to 39 age range for Black men and in the 35 to 39 age range for White men [36]. Nonseminoma incidence rates peaked in the 20 to 24 age range for Hispanic, AI/AN and API men [36] and in the 25 to 29 age range for Black men [26, 36]. Contrasting results were reported for White men, while one research group reported that nonseminoma incidence rates peaked for White men in the 20 to 24 age range [26], while others reported peak incidence rates in the 25 to 29 age range [36]. These differing results may be an artifact of the chosen dataset. While one study only used data from SEER [26], the other study used data from NPCR and SEER [36]. The study that only used SEER data included a larger range of years for cases (1973 to 2001) [26], while the study used both NPCR and SEER to create the sample limited cases to 1999 through 2004 [36]. These methodological differences may explain the contrasting findings.

Advanced stage Hodgkin's lymphoma (HL). Among males aged 15 to 24, a higher portion of those diagnosed with advanced stage HL were Black males [34]. Among males aged 24 to 34 and 35 to 39, a higher portion of those diagnosed with advanced stage HL were Hispanic males [34]. Among 35 to 39-year-old females, a higher portion of those diagnosed with advanced stage HL were Hispanic females [34]. While this study concludes that rates are highest for Hispanic and Black patients, it does not provide any information about how race varies with age for other

racial groups including API, AI/AN, biracial or multiracial. It would be important to consider whether other cross-over effects exist for other racial groups.

Gender. Four studies included in this review investigated gender differences associated with cancer incidence and mortality [9, 15, 22, 37]. Three of the four studies examined gender differences among melanoma patients [9, 15, 37], while one study examined overall prevalence of cancer among a national population survey sample [22]. Based on data from the population survey that included cancer survivors, women were more likely to report having more than one cancer as compared to men [22].

Melanoma incidence rates were higher among females as compared to males [9, 15, 37]. While some researchers reported that incidence rates were higher for females across the entire 15 to 39 age range [15, 37], others reported that incidence rates were higher for females aged 15 to 29 but then it crossed over, and males experienced higher incidence rates between the ages of 35 and 39 [9]. Mortality risk was higher among males as compared to females across the entire 15 to 39 age range [9, 15]. Furthermore, researchers reported that males were more likely to be diagnosed with regional or distant stage disease as compared to females [37]. While incidence and mortality information for melanoma are important, additional studies need to examine other cancers aside from the four included here to determine if gender differences exist. As well, no study included intersex or transsexual participants.

Insurance status. Five studies included in this review investigated how insurance was associated with cancer incidence and mortality rates [1, 8, 20, 30, 34]. Two studies considered differences across all cancers among those 15 to 39 [1, 30], while one study each focused on cervical cancer [8], advanced stage HL [34], and non-Hodgkin's lymphoma [20]. Researchers reported that a higher relative risk for those with Medicaid, Medicare, or without insurance for

melanoma and skin carcinomas, thyroid carcinoma, carcinoma of the breast, and carcinoma of the genitourinary tract as compared to those with insurance [30]. It was commented that these cancers are commonly detected through preventative screening, which is more likely to be done among individuals who have insurance [30]. Whereas, those without insurance experienced a lower risk for carcinoma of the trachea, bronchus, and lung; carcinoma of other and ill-defined sites as compared to those with insurance [30].

Across all cancers, males and females without insurance were more likely to be diagnosed with a distant stage cancer as compared to males and females with insurance [30]. Having insurance was reported to be associated with the decreased incidence of metastatic disease and that this relationship remained statistically significant even after adjusting for other demographic variables [1]. Similarly, lower incidence of advanced stage HL [34] and advanced stage cervical cancer [8] was reported among those with private insurance as compared to no insurance.

Insurance status was also reported to be associated with survival rates among 15 to 39 year olds with cancer [1, 20]. Having insurance was associated with lower estimates of mortality across all cancers, even after adjusting for other demographic variables [1]. Private insurance among Hispanic/Latino patients was reported to be associated with higher survival, while public insurance among Black patients was associated with lower survival [20]. However, none of these studies examined the type or kind of insurance coverage patients had, the amounts of copays or deductions, or the cost of treatment.

Neighborhood socioeconomic status. Three studies investigated the effect of neighborhood socioeconomic status (nSES) on cancer incidence and mortality [11, 20, 34]. Individual SES data is not collected by most US cancer registries [11]; thus, researchers often

use a neighborhood level SES as a proxy for individual SES based on participants' residential address at time of diagnosis and census level SES data (Diez Roux et al., 2001; Yost, Perkins, Cohen, Morris, & Wright, 2001). Neighborhood SES (nSES) is a composite score based on census level measures of education, income, and occupation (Yost et al., 2001). Lower nSES was associated with higher incidence of non-Hodgkin's lymphoma [20] and advanced stage HL [34]. Higher nSES was associated with higher relative and absolute risk of melanoma [11]. All of these studies used the California Cancer Registry, limiting the generalizability of these findings beyond California. Other local and national registries should consider how to assess and incorporate individual SES factors into their data collection. SES is an important factor associated with many health-related outcomes (Barr, 2014; Braveman, Egerter, & Williams, 2011; Chen & Miller, 2013). However, SES has been identified as being complex and problematic to assess within the context of healthcare research (Braveman et al., 2005).

United States region. One study investigated regional differences associated with cancer incidence and mortality rates [30]. A slightly higher risk of a distant stage diagnosis was reported among men treated in the Midwest, South and West, as compared to the Northeast [30]. A slightly higher risk of distant stage disease was only identified for women treated in the West [30]. A higher incidence of distant stage disease among those treated at NCI-designated facilities was also reported [30]. This study did not include any information about why these differences exist. Understanding why the differences exist is important for developing regional policies to address these health disparities. Future studies should also consider differences by city size, location, resources, cancer center characteristics, and other factors that may be associated with regional differences.

Marital status. One study reported on the effect of marital status on incidence and mortality rates among young adults with cancer [20]. Higher survival from non-Hodgkin's lymphoma was reported for those married as compared to unmarried patients [20]. However, this study did not examine how incidence and mortality varied beyond two categories of marital status (i.e., married vs. not married). Additional analyses could examine whether rates differ among widowed or divorced individuals.

Nearly all of the studies reported in Theme 1 used data from national or regional cancer registries, limiting the extent to which sociodemographic variables were collected. Sociodemographic variables such as education level, individual SES, nation of origin, and religious affiliation were not reported among these studies, providing an incomplete picture of the role of sociodemographic variables in the incidence and mortality of cancer among young adults. Furthermore, very few studies reported results for the intersection or interaction among sociodemographic variables [17, 26, 34 - 36]. One of the benefits of using cancer registries is the potentially large sample size, which is beneficial for advanced statistical models that can consider the interactions and main effects of multiple sociodemographic variables.

Theme 2: Access to Care

Eighteen studies included in this review reported on the association between sociodemographic variables and access to care for patients aged 15 to 39. Studies reported differences in insurance status [1, 22, 30, 34], time to diagnosis [25], treatment [28], clinical trial participation [28], receiving definitive therapy [1], rates of patients treated at a NCI-designated, Children Oncology Group Institution, or an American College of Surgeons cancer center [2, 14, 38], receiving ongoing medical care [19], and cancer-related fertility counseling [23]. As well, several studies reported cancer-specific access to care including differences in cervical cancer

screening rates [5, 12, 31, 32], cervical cancer treatment modalities [10], and mammography rates [33]. Studies that reported on the association between sociodemographic variables and differences in access to care among young adults with cancer are provided in Table 4. One of the biggest drawbacks of these studies is that gathering information about access to care is difficult to do if the patient is not entering the healthcare system, which provides an incomplete picture of the current disparities.

Having insurance. Four studies included in this review investigated sociodemographic variables associated with having or not having insurance [1, 22, 30, 34]. Based on the 2009 data from the BRFSS, it was reported that female cancer survivors were more likely to be uninsured as compared to non-cancer survivors, whereas rates among male survivors and non-survivors did not differ [22]. Furthermore, it was reported that White, Black, and other race survivors had similar levels of being uninsured and did not significantly differ from controls [22]. However, Hispanic survivors and non-survivors had higher levels of being uninsured as compared to non-Hispanic survivors and non-survivors [22].

Among cancer patients aged 15 to 39 with all cancer types, being uninsured as compared to being insured, was associated with being male, younger, not White, not married, from a lower neighborhood income level, less educated, and from a rural area [1, 30]. Similar findings were reported for advanced stage HL; males were more likely to be uninsured as compared to females and there was a lower incidence of advanced stage HL among those with private insurance as compared to those without insurance [34]. None of these studies examined the interaction of multiple sociodemographic variables and its relationship to insurance status. Consideration of interactions is important for understanding the complexity of the disparities. As well, none of these studies examined the amount of insurance that participants had. Having insurance is not the

same as having full coverage or insurance with low premiums or deductibles, thus future studies need to provide a more in-depth measure of insurance in order to assess how much access to care AYA patients have.

Time to diagnosis and treatment. Two studies included in this review investigated sociodemographic variables associated with differences in the time it takes for patients to receive a diagnosis [25] and to begin treatment [28]. Among a sample that included leukemia, Hodgkin's and non-Hodgkin's lymphoma, sarcoma, brain tumors, and thyroid cancer, patients with public insurance experienced on average a 6.9-week delay in receiving a diagnosis as compared to patients with private insurance [25]. Patients with public insurance a 13.1-week delay as compared to self-pay patients [25]. Furthermore, researchers reported no differences in time to diagnosis by age, gender, race, ethnicity, marital status, or zip code of residence [25]. No other sociodemographic variables, such as education or income were assessed.

One study examined delays in beginning treatment and differences associated with gender and race and found that median time to treatment was longer among females as compared to males [28]. However, this is heavily skewed by germ cell, which is a primarily male cancer and is treated with surgery. When germ cell cancers are excluded from the analysis, males and females experience a similar median time to treatment [28]. Furthermore, 10% of Black patients and 8% of Asian/Pacific Islander patients were reported to have had a two-month lag for first treatment, in a sample that included Hodgkin's and non-Hodgkin's lymphoma, acute lymphoblastic leukemia, germ cell cancer, and three types of sarcoma (i.e., osteo-, Ewing-, and synovial), which is significantly greater than the number of White patients that experienced a lag [28]. While one study focused on the association of insurance with receiving a diagnosis [25], the other assessed the association between gender and race with delays in treatment [28]. There

is no overlap between these two studies regarding how sociodemographic variables are associated with diagnosis and treatment delays. Studies need to look at both factors within the same sample. Other studies should also consider cultural factors in how patients receive a diagnosis and receive treatment as delays may not be due to healthcare systems and may be related to patients' views of health and healthcare.

Clinical trial participation. One study included in this review investigated sociodemographic variables associated with differences in clinical trial participation [28]. Among a sample that included Hodgkin's and non-Hodgkin's lymphoma, acute lymphoblastic leukemia, germ cell cancer, and osteo-, Ewing-, and synovial sarcomas, higher clinical trial participation was reported for those aged 15 to 19 as compared to those 35 to 39 years old [28]. Higher clinical trial participation was reported for non-Hispanic Black as compared to non-Hispanic White patients and among those with Medicaid or private insurance as compared to HMO or no insurance [28]. This study provides a very incomplete picture about clinical trial participation among AYAs by only examining age, race, and insurance status [28]. Additional studies should examine why some people choose to participate in clinical trials and why others do not, and how these decisions are associated with the intersection of multiple sociodemographic variables.

Receiving definitive therapy. One study included in this review investigated sociodemographic variables associated with receiving definitive therapy across all cancer types [1]. Patients with insurance were more likely to receive definitive therapy, such as surgery and/or radiotherapy, even after adjusting for other demographic variables [1]. However, this study did not evaluate the extent of the insurance coverage or other socioeconomic factors.

Treatment at a National Cancer institute or an American College of Surgeons designated cancer center. Three studies included in this review investigated sociodemographic variables associated with being treated at a National Cancer Institute (NCI) or an American College of Surgeons (ACS) designated cancer center [2, 14, 38]. Howell and colleagues (2007) reported that only 36% of 15 to 19 year olds were treated at an NCI-designated Children Oncology Group (COG) institution. Patients aged 22 to 39 were less likely to be seen at an NCI Comprehensive Cancer Center (CCC) or COG institution as compared to those aged 15 to 21 [38]. Among those aged 22 to 39, having public or no insurance, being lower SES, and living more than 5 miles from the cancer center was associated with not being seen an NCI-CCC institution [14].

Only 34% of 15 to 19-year-olds patients and less than 1% of 19 to 24-year-olds were treated at the Primary Children's Medical Center (PCMC), which is the only medical center in Utah staffed with Pediatric Oncologists [2]. Non-White patients aged 15 to 19 were more often seen at PCMC, as compared to White patients [2]. Furthermore, only 13% of 15 to 19-years-olds and 21% of 20 to 24-year-olds were never seen at an ACS cancer center [2]. None of these studies examined why the rates are low or examine where else patients are being treated.

Ongoing medical care. One study included in this review investigated sociodemographic variables associated with differences in ongoing medical care among cancer survivors [19]. Among a sample of cancer survivors aged 15 to 39, which included survivors from Hodgkin's and non-Hodgkin's lymphoma, germ cell cancer, acute lymphocytic leukemia, Ewing's, osteo-, and rhabdomyo-sarcoma, those without insurance were less likely to go to the doctor as compared to those with insurance [19]. High cost and lack of insurance was noted as the top reasons for not going to a doctor's visit [19]. Among those survivors that reported not going to

any cancer-related visits in the previous year, a higher portion of them were male, Black, AI/AN or Hispanic, unemployed, and had no insurance [19]. While this study included multiple social locations, going to a doctor or having a cancer-related visit is vague and does not provide sufficient information about patients' ongoing access and receipt of medical services. Additional studies could assess whether patients receive survivorship plans and possibly whether cancer teams are collaborating with primary care providers as patients move back to primary care.

Cancer-related fertility counseling. One study included in this review investigated sociodemographic variables associated with differences in receiving cancer-related fertility counseling [23]. Among a sample of 18 to 40-year-old cancer patients, which included Hodgkin's and non-Hodgkin's lymphoma, leukemia, breast cancer, and gastrointestinal cancer, older age, the desire for children, and increased education level was associated with the odds of receiving fertility counseling [23]. Lower income was associated with being less likely to receive fertility counseling [23]. A higher odd of pursuing fertility preservation was associated with higher age at diagnosis, a desire for children, having children at diagnosis, and a higher education level [23]. A trend towards decreased access to fertility counseling was reported for Latinas, as compared to White women [23]. Within the sample, none of the Black women or non-heterosexual women reported completing fertility preservation [23]. More than 50% of eligible participants declined participation in this study, which presents the possibility of a biased sample [23]. Additional studies are needed to understand the role of sociodemographic variables associated with receiving and not receiving cancer-related fertility counseling. It would be important to examine whether patients are being offered services and not using them or are simply not being offered services.

Cervical Cancer Screening Rates. Four studies included in this review investigated sociodemographic variables associated with cervical cancer screening rates [5, 12, 31, 32]. As compared to national guidelines, researchers reported that 24% of individuals aged 18 to 20 were screened too early for cervical cancer [12]. The percentage screened early was highest for Black women [12]. Missing screening rates were highest among Hispanic women, foreign-born women, and among those with a gap in or no insurance [12].

The age of first Pap test was reported to be younger for Black women and older for Hispanic and Asian women as compared to White women [31]. Age of first Pap was also younger for women with less than a high school education, as compared to those with a college degree or greater [31]. Having a usual source of healthcare and the use of birth control was associated with having a Pap test within the previous 12 months [31]. Other researchers reported that Hispanic women were less likely to have a Pap test in the previous 12 months as compared to White and Black women [32]. White and Hispanic women with partial insurance were less likely to have a Pap test as compared to peers with continuous insurance [5]. These studies examined Pap test rates among patients that were seen at healthcare centers or contacted through national surveys; however, this is not a representative sample of the population. Greater disparities may be experienced by those not assessed. Furthermore, none of these studies examined rates for follow up treatment.

Cervical cancer treatment modalities. One study included in this review investigated sociodemographic variables associated with cervical cancer treatment modalities [10]. Higher rates of a total hysterectomy were reported among White women as compared as non-White women [10]. Receiving radiotherapy as a primary treatment, compared to receiving surgery, was associated with worse survival [10]. Receiving radiotherapy as a primary treatment was

associated with having a higher stage cancer, being widowed or single, and not being White [10]. Researchers reported that the region of the US, education level, income, age, and cancer stage were not associated with receiving radiotherapy as a primary treatment [10]. This study dichotomized race as White and non-White, which fails to consider the complexity of race. As well, the interaction of sociodemographic variables was not assessed.

Mammography rates. Only one study included in this review investigated sociodemographic variables associated with mammography rates [33]. Among a sample of women between the ages of 18 and 33, mammography rates were higher among Black women as compared to White women [33]. Mammography rates were similar between Black and White women between the ages of 34 and 40 [33]. This study only included Black and White women and did not include any information about follow up rates.

Overall studies across Theme 2 that examined access to care provided valuable information about how AYAs are not getting the care that they need from screening through follow-up care. However, these studies taken together do not provide a full picture, as most studies only included a few sociodemographic variables rather than considering all of them. Additional studies that capture complete information about sociodemographic variables are necessary. As well, the studies included here included samples captured through national surveys or identified through cancer registries, which may not include those individuals who experience the greatest challenges accessing care. Next, articles about unmet supportive care needs are presented.

Theme 3: Unmet Health and Supportive Care Needs

Five studies included in this review reported on the association between sociodemographic variables and unmet health and supportive care needs among cancer patients

and survivors aged 15 to 39 [19, 39 – 42]. One study only included survivors in the study [41], while another only included patients in the study sample [40]. All of the other studies included a mix of patients and survivors [19, 39, 42]. Studies that investigated unmet needs are provided in Table 5 and are organized by sociodemographic variables. Of all the studies included in this entire systematic review, these studies provided the most information regarding the association between sociodemographic variables and the theme, unmet supportive care needs. This is likely because these studies included author-designed questionnaires, and authors were cognizant of the importance of capturing thorough sociodemographic information. The gaps in these results and the literature on unmet supportive care will be discussed at the end of this section, rather than with each subcategory.

Age. Four studies included in this review investigated sociodemographic variables associated with unmet health and supportive care needs [19, 39, 40, 32]. Patients between the ages of 18 and 29 reported a greater need for fertility services, scheduling treatments that fit their lifestyles, and support from family and friends [42], however, it is unclear what specific ages are considered ‘younger.’ Other studies reported that those aged 20 to 29 reported the greatest need for fertility counseling [39, 40]. Patients between the ages of 18 to 29 were reported to have a greater need for infertility information, infertility treatment/services, and adoption services as compared to those aged 30 to 40 [40]. Those aged 20 to 39 reported a greater unmet need for websites for education and support, information about cancer, infertility, nutrition and diet, mental health, religious, and spiritual counseling, as well as complementary alternative medicine services as compared to those aged 15 to 19 [39].

Those aged 30 to 39 reported the greatest need for family counseling, transportation services and assistance with insurance, social security benefits and disability [39]. Older patients

within the 18 to 40 age range reported a greater unmet need for access to multiple medical opinions, state-of-the-art treatment, and greater responsibility for one's own health care and decision making [42]. Among a sample of 15 to 39-year-old cancer patients, which included Hodgkin's and non-Hodgkin's lymphoma, germ cell cancers, acute lymphocytic leukemia and sarcoma, specifically Ewing's osteo- and rhabdomyosarcoma, those aged 30 to 39 reported more unmet needs related to treatment, possible long term-side effects, financial support for care and concern about getting another type of cancer [19].

Needs among younger and older off treatment participants were slightly different [42]. Older individuals who are no longer on treatment reported a greater need for counseling and support for managing distress, having providers who know about long-term follow-up care, and assistance in finding survivor support groups [42]. Younger individuals reported a greater need for information about fertility and reproduction options, support from friends and family, and encouragement to engage in social activities.

Race/ethnicity. Four studies included in this review investigated the association between racial/ethnic differences and unmet health and supportive care needs [19, 39 – 41]. Non-White participants (both patients and survivors) with any invasive cancer reported more often an unmet need for information, assistance with insurance, disability, and social security benefits [39]. There were mixed findings the need for family counseling, where one study reported that non-White patients reported a greater need for family counseling as compared to White patients [41], the other reported that White patients had a higher need for family counseling [39].

Among a sample that included Hodgkin's and non-Hodgkin's lymphoma, germ cell cancers, acute lymphocytic leukemia and sarcoma, Black, AI/AN or Hispanic participants reported a greater unmet need related to recurrence, treatment, and financial support [19]. As

compared to White participants, Black, AI/AN and Hispanic participants reported more than 6 unmet information needs [19]. Among survivors of all cancers except brain tumors and thyroid cancer, non-White (as compared to White) participants reported a higher need for internet site, diet and nutrition information, exercise information, mental health counseling, family counseling, counseling related to sexuality, infertility information, complementary alternative medicine services and transportation services [41].

Gender. Four studies included in this review investigated how unmet health and supportive care needs differed by gender [19, 39, 41, 42]. Across all cancers, females ranked the need for minimizing side effects, age-appropriate information about cancer, psychological counseling and opportunities to meet other people with cancer as higher than males [42]. Among participants with any invasive cancer, females reported a greater need for religious or spiritual counseling, while men reported a higher need for sexuality or intimacy counseling [39]. Similar unmet needs were reported for female survivors, including a higher need for infertility information, adoption services, camps, retreats and counseling related to sexuality [41]. Male survivors reported a higher need for alcohol or drug counseling and assistance with transportation [41]. Among a sample that included Hodgkin's and non-Hodgkin's lymphoma, germ cell cancer, acute lymphocytic leukemia, or sarcoma, males more often reported more than six unmet information needs [19].

Employment status. Only one study included in this review investigated the association between employment status and unmet needs [41]. Among a sample of survivors that included all cancers but brain tumors and thyroid cancer, found that unemployed as compared to employed survivors reported a higher need for information about cancer, exercise information,

transportation assistance, mental health counseling, family counseling, and counseling related to sexuality [41].

Education level. Two studies included in this review investigated the association between education level and unmet needs [40, 41]. Among cancer survivors, those with less than a college degree reported a higher need for information about cancer, internet sites, complementary alternative medicine services, assistance with transportation and childcare, information about diet, nutrition, and exercise, as well as mental health, religious/spiritual and alcohol or drug counseling [41]. Among cancer patients, a higher portion of those participants that indicated a need for Internet sites did not have a college degree [40].

Marital status. Two studies included in this review investigated the association between marital status and unmet needs [40, 41]. Among cancer survivors, unmarried participants reported a higher need for information about cancer, internet sites, infertility information, infertility services, camps/retreats, transportation assistance, as well as religious/spiritual counseling and alcohol or drug counseling [41]. Married survivors reported a higher need for information about diet and nutrition and childcare assistance [41]. Among cancer patients, unmarried participants reported a greater need for infertility treatment as compared to married participants [40].

The five studies included in theme 3 that examined the relationship between sociodemographic variables and unmet supportive care provide valuable information for addressing the diverse needs of AYA patients. However, there are some limitations that should be considered. Several of these studies used online surveys with a convenience sample [19, 40 – 42], which limits the generalizability of the sample. Several of the studies included a predominantly female, White, educated sample [40 – 42], limiting the findings to more diverse

patients. However, one study included a large sample of Hispanic/Latino participants [39]. Another limitation of these studies includes the use on non-validated, author-designed surveys. The final limitation is that none of these studies examined the interaction of multiple sociodemographic variables.

Discussion

The 42 studies included in this systematic review illustrate the complexity of disparities faced by AYA oncology patients in relation to sociodemographic variables. Among AYAs, there are sociodemographic variables associated with disparities in the incidence of and mortality from cancer, access to screening, treatment and post-cancer care, as well as unmet health and supportive care needs. Among the articles that examined incidence and mortality, studies most consistently included age, race/ethnicity and gender as sociodemographic variables (e.g., (Denslow et al., 2012; Holmes et al., 2008; Weir et al., 2011)). Several additional studies also examined the association between insurance status (e.g., Fedewa et al., 2012), neighborhood status (e.g., Hausauer, Swetter, Cockburn, & Clarke, 2011), United States region (Robbins et al., 2014) and marital status (Kent et al., 2010), however there were fewer of these studies.

Across these studies, excluding studies that focused on melanoma, the findings suggest that older AYAs (Denslow et al., 2012; Holmes et al., 2008; Kent et al., 2009), non-White patients (Desantis, Jemal, & Ward, 2010; Joslyn, Foote, Nasser, Coughlin, & Howe, 2005; Kent et al., 2010), those without private insurance (Aizer et al., 2014; Robbins et al., 2014; Smith et al., 2012), lower neighborhood SES (Kent et al., 2010; Smith et al., 2012), not being treated in the Northeast region of the United States (Robbins et al., 2014) and being unmarried (Kent et al., 2010) have the worst outcomes related to incidence and mortality. The findings for melanoma cancer are significantly different, as increased incidence and mortality are associated with being

white (Gamba, Clarke, Keegan, Tao, & Swetter, 2013; Jemal et al., 2011; Weir et al., 2011) and living in a higher SES neighborhood (Hausauer et al., 2011). Among these studies, very few researchers examined the interaction of multiple sociodemographic variables. The interaction of age and race was the only identified in this review (Joslyn et al., 2005; McGlynn, Devesa, Graubard, & Castle, 2005; Smith et al., 2012; Tarone, 2006; Townsend, Richardson, & German, 2010). Patients do not experience each sociodemographic variable in isolation, thus it is necessary to understand the study sample in its entirety rather than as divided variables.

As compared to studies that assessed incidence and mortality, there were significantly fewer studies that examined some aspect of access to care among AYA oncology patients and non-patients seeking cancer screenings. As well, there was even less consistency regarding what sociodemographic variables were examined. The length of time to a diagnosis or beginning treatment, receiving definitive therapy and receiving ongoing medical care among AYAs was associated with being younger (Aizer et al., 2014; Robbins et al., 2014), not White (Aizer et al., 2014; Keegan et al., 2014; Parsons, Harlan, Seibel, Stevens, & Keegan, 2011; Robbins et al., 2014), unmarried (Aizer et al., 2014), living in low SES neighborhood (Robbins et al., 2014), and not having private insurance (Aizer et al., 2014; Keegan et al., 2014; Martin et al., 2007). Parson and colleagues (2011) reported contrasting findings for clinical trial participation. Non-white, older and those with Medicaid or private insurance were more likely to be enrolled in clinical trials (Parsons et al., 2011).

Studies that examined cervical cancer screenings reported conflicting findings regarding the role of insurance. While Henderson and colleagues (2012) concluded that having insurance appears to be an important factor for receiving timely cervical cancer screenings, Cowburn and colleagues (2013) reported conflicting findings. Hispanic women were more likely to receive a

Pap test if they did not have insurance while White women were more likely to receive a Pap test if they had continuous insurance (Cowburn, Carlson, Lapidus, & Devoe, 2013). However, these studies did not examine multiple sociodemographic variables.

Of all of the studies included in this systematic review, the five studies that examined unmet health and supportive care needs included the greatest number of sociodemographic variables in their analyses. The five studies included reported on the association of unmet needs with age, race/ethnicity, gender, employment status, education level, and marital status (Keegan et al., 2012; Zebrack, 2008, 2009; Zebrack et al., 2013; Zebrack, Mills, & Weitzman, 2007). The inclusion of these demographic variables across studies is likely due to similar survey instruments being used across studies. Overall, higher unmet health and supportive care needs were associated with being not white, not employed and having a lower level of education (Keegan et al., 2012; Zebrack, 2008, 2009; Zebrack et al., 2013; Zebrack et al., 2007). Unmet needs associated with age or gender were not consistent across studies.

Across the three main themes examined through this review, these studies support previous findings about the association of age, gender and race/ethnicity with disparities among AYAs (Howlader et al., 2014; NCI, 2012). However, through this review, there is sufficient evidence to suggest that insurance status, socioeconomic status and education (Aizer et al., 2014; Kent et al., 2010; Smith et al., 2012) are important to the experience of disparities among AYA patients and need to be further evaluated. Researchers need to include additional intersecting variables, such as education, individual and neighborhood socioeconomic status in order to develop a comprehensive picture of the disparities. Having a more comprehensive understanding will be beneficial to systemically addressing disparities faced by AYA patients.

Implications for Future Research and Practice

As seen from this systematic review, more research is needed to understand the heterogeneity of this patient population and how this heterogeneous patient population experiences incidence, mortality, access to care and unmet needs. Intersectionality theory (Crenshaw, 1989, 1991, 1995) provides a framework for understanding these complexities and is useful for developing services targeted to reach the most marginalized portions of the sample (Cole, 2009). AYA researchers have made substantial progress toward this goal by identifying the disparities that AYA patients face as compared to pediatric and older adult patient populations, but it is now time to shift the attention to understanding and addressing the disparities within the group. It is time to start with the patient population and understand the disparities faced by this population (Cole, 2009). The studies included here provide a brief overview of some of these disparities associated with age, race, gender, insurance status, United States region, neighborhood status, and marital status, but many gaps still exist. None of the studies included in this study examined individual patients' education level, income, immigration status, religious or spiritual beliefs or sexual orientation. As well, not all cancers were equally represented across the studies.

One approach to increasing the current knowledge is to expand national datasets, such as SEER, and NCDB, to include additional sociodemographic variables such as income, education level, sexual orientation, distance to cancer center, spirituality, living conditions, and nation of origin. Age, race and gender are important sociodemographic variables, but by placing greater emphasis on these without considering others, the findings about AYAs are incomplete. National and local cancer registries are invaluable to ongoing epidemiological studies. Thus, capturing more data about participants is important for building the evidence base, which is necessary for

understanding the patient population. Including more variables will help researchers understand the complexity of patients and their experiences with health.

With larger sample sizes available through the national datasets, researchers have a greater potential of examining the intersection of multiple sociodemographic variables or comparing outcomes among different groups that include multiple sociodemographic variables (instead of controlling for those variables). For example, researchers could compare White, lesbian women to Black, heterosexual, males. Each of these sociodemographic variables are not experienced in isolation (Crenshaw, 1989, 1991, 1995) but instead aggregate to be the patient's lived experience, thus as researchers, we need to keep those sociodemographic variables together rather than separating their variability. This can be done by stratifying samples based on multiple sociodemographic variables, assessing interaction terms or developing more advanced statistical models.

Other efforts should be directed towards understanding disparities experienced at the community or cancer center level. National information may not be representative of the disparities faced in particular communities. For example, the SEER database only accounts for approximately 26% of the United States population and many of these registries are housed with large academic cancer centers (Ries et al., 2008). Additional efforts need to be made to connect with community cancer centers to examine how disparities may differ between academic and community cancer centers in rural and urban locations.

Additional efforts are necessary to engage with the AYA population to understand the challenges they face in being diagnosed with and receive treatment for cancer. National datasets and surveys do not reach all AYAs, and may provide a biased view of their challenges and disparities. AYAs are split across pediatric and adult medical oncology settings (e.g., Bleyer et

al., 2008), as well as and in academic and community cancer centers. As a result of being spread across multiple settings, they do not comprise a large portion of any clinic's patient population, contributing to their invisibility (Haase & Phillips, 2004). To account for this, researchers need to engage with AYAs through non-profit and advocacy organizations that are highly utilized by AYAs, such as StupidCancer and SAMFund. As well, it may be important to identify the resources that AYAs are engaged with, such as pharmacy, support groups, nutrition services and financial counseling (Zebrack et al., 2013) and connect with patients through these services. These services are typically shared by multiple clinics within a cancer center so they may see a larger portion of AYAs than any one particular cancer clinic.

Limitations

There are two important limitations to consider with this systematic review. First, this study only included peer-reviewed, English-language, published articles. There are likely other reports that provide valuable information about incidence, prevalence, and mortality, access to care and psychosocial outcomes among AYAs with cancers that are not published in journals, and thus were not included in this systematic review. Second, although the first author worked closely with an academic librarian to identify search terms that would increase the likelihood of capturing all of the relevant articles, and had a second reviewer repeat the search, there is always the possibility of missing articles. Incidence, prevalence, mortality, access to care and unmet needs are complex concepts and the search terms selected for this study may have missed some articles pertaining to these concepts.

Conclusion

In the ongoing efforts to improve care, and ultimately survival, for AYA oncology patients, it is important to consider how sociodemographic variables, and the intersection of

multiple sociodemographic variables, are associated with disparities faced by AYA patients. Disparities faced by AYA patients provide valuable information for program developers, researchers, and policy makers as the field of AYA oncology continues to grow. It is time for researchers and clinicians to expand their conceptual framework and embrace an approach, such as IT, to understand the disparities experienced by AYA oncology patients, and how those disparities are associated with the intersection of age, gender, ethnicity, sexual orientation, nation of origin, and socioeconomic status. If the purpose of national guidelines and organizations is to increase survival rates for AYA patients (AYAO PRG, 2006; Coccia et al., 2012; IOM, 2007), then it is necessary to understand the complexity of these disparities within the AYA patient population.

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Table 1

Article Search Summary.

CINAHL via EbscoHost	PsychInfo via EbscoHost	Medline via PubMed
<u>Filters:</u> published between 1/1/2005 and 2/20/2015; adult: 19-44 years old; English language	<u>Limiters:</u> published between 1/1/2005 and 2/20/2015; young adulthood (18-29 yrs), thirties (30-39 yrs); English language	<u>Filters:</u> published in last 10 years; adult: 19-44 years old; English language
neoplasms AND incidence AND young adult* Found: 133 Yield: 1	neoplasms AND incidence* AND young adult* Found: 10 Yield: 0	neoplasms AND incidence AND ethnic groups AND young adult* Found: 118 Yield: 9
		neoplasms AND incidence AND disabled persons AND young adult* Found: 2 Yield: 0
		neoplasms AND incidence AND educational status AND young adult* Found: 12 Yield: 0
		neoplasms AND incidence AND rural health AND young adult* Found: 2 Yield: 0
		neoplasms AND incidence AND urban health AND young adult* Found: 3 Yield: 0

(continued) neoplasms AND incidence AND young adult* Found: 133 Yield: 1	(continued) neoplasms AND incidence* AND young adult* Found: 10 Yield: 0	neoplasms AND incidence AND socioeconomic factors AND young adult* Found: 102 Yield: 3
		neoplasms AND incidence AND insurance AND young adult* Found: 10 Yield: 0
		neoplasms AND incidence AND healthcare disparities AND young adult* Found: 11 Yield: 0
		neoplasms AND incidence AND health status disparities AND young adult* Found: 20 Yield: 0
oncology AND incidence AND young adult* Found: 1 Yield: 0	oncology AND incidence* AND young adult* Found: 0 Yield: 0	medical oncology AND incidence AND young adult* Found: 4 Yield: 0
neoplasms AND prevalence AND young adult* Found: 92 Yield: 0	neoplasms AND prevalence* and young adult* Found: 18 Yield: 0	neoplasms AND prevalence AND ethnic groups AND young adult* Found: 41 Yield: 0
		neoplasms AND prevalence AND disabled persons AND young adult* Found: 2 Yield: 0
		neoplasms AND prevalence AND educational status AND young adult* Found: 17 Yield: 0

(continued) neoplasms AND prevalence AND young adult* Found: 92 Yield: 0	(continued) neoplasms AND prevalence* and young adult* Found: 18 Yield: 0	neoplasms AND prevalence AND rural health AND young adult* Found: 1 Yield: 0
		neoplasms AND prevalence AND urban health AND young adult* Found: 5 Yield: 0
		neoplasms AND prevalence AND socioeconomic factors AND young adult* Found: 89 Yield: 0
		neoplasms AND prevalence AND insurance AND young adult* Found: 13 Yield: 0
		neoplasms AND prevalence AND healthcare disparities AND young adult* Found: 3 Yield: 0
		neoplasms AND prevalence AND health status disparities AND young adult* Found: 7 Yield: 0
		oncology AND prevalence AND young adult* Found: 1 Yield: 0
oncology AND prevalence* AND young adult* Found: 2 Yield: 0		
medical oncology AND prevalence AND young adult* Found: 5 Yield: 0		
neoplasms AND mortality AND young adult* Found: 36 Yield: 0		
neoplasms AND mortality rate AND young adult* Found: 1 Yield: 0		
neoplasms AND mortality AND ethnic groups AND young adult* Found: 70 Yield: 1		

(continued) neoplasms AND mortality AND young adult* Found: 36 Yield: 0	(continued) neoplasms AND mortality rate AND young adult* Found: 1 Yield: 0	neoplasms AND mortality AND disabled persons AND young adult* Found: 2 Yield: 0
		neoplasms AND mortality AND educational status AND young adult* Found: 13 Yield: 0
		neoplasms AND mortality AND rural health AND young adult* Found: 1 Yield: 0
		neoplasms AND mortality AND urban health and young adult* Found: 1 Yield: 0
		neoplasms AND mortality AND socioeconomic factors AND young adult* Found: 76 Yield: 0
		neoplasms AND mortality AND insurance AND young adult* Found: 15 Yield: 0
		neoplasms AND mortality AND healthcare disparities AND young adult* Found: 18 Yield: 0
		neoplasms AND mortality AND health status disparities AND young adult* Found: 17 Yield: 0

oncology AND mortality AND young adult* Found: 0 Yield: 0	oncology AND mortality rate AND young adult* Found: 0 Yield: 0	medical oncology AND mortality AND young adult* Found: 17 Yield: 0
neoplasms AND morbidity AND young adult* Found: 8 Yield: 0	neoplasms AND morbidity AND young adult* Found: 2 Yield: 0	neoplasms AND morbidity AND ethnic groups AND young adult* Found: 159 Yield: 0
		neoplasms AND morbidity AND disabled persons AND young adult* Found: 4 Yield: 0
		neoplasms AND morbidity AND educational status AND young adult* Found: 29 Yield: 0
		neoplasms AND morbidity AND rural health AND young adult* Found: 3 Yield: 0
		neoplasms AND morbidity AND urban health AND young adult* Found: 9 Yield: 0
		neoplasms AND morbidity AND socioeconomic factors AND young adult* Found: 190 Yield: 0
		neoplasms AND morbidity AND insurance AND young adult* Found: 22 Yield: 0

(continued) neoplasms AND morbidity AND young adult* Found: 8 Yield: 0	(continued) neoplasms AND morbidity AND young adult* Found: 2 Yield: 0	neoplasms AND morbidity AND healthcare disparities AND young adult* Found: 15 Yield: 0
		neoplasms AND morbidity AND health status disparities AND young adult* Found: 27 Yield: 0
oncology AND morbidity AND young adult* Found: 0 Yield: 0	oncology AND morbidity AND young adult* Found: 0 Yield: 0	medical oncology AND morbidity AND young adult* Found: 9 Yield: 0
neoplasms AND survival AND young adult* Found: 98 Yield: 1	neoplasms AND survival* AND young adult* Found: 20 Yield: 0	neoplasms AND survival rate AND ethnic groups AND young adult* Found: 62 Yield: 0
		neoplasms AND survival rate AND disabled persons AND young adult* Found: 2 Yield: 0
		neoplasms AND survival rate AND educational status AND young adult* Found: 9 Yield: 0
		neoplasms AND survival rate AND rural health AND young adult* Found: 0 Yield: 0
		neoplasms AND survival rate AND urban health AND young adult* Found: 0 Yield: 0

(continued) neoplasms AND survival AND young adult* Found: 98 Yield: 1	(continued) neoplasms AND survival* AND young adult* Found: 20 Yield: 0	neoplasms AND survival rate AND socioeconomic factors AND young adult* Found: 45 Yield: 0
		neoplasms AND survival rate AND insurance AND young adult Found: 9 Yield: 0
		neoplasms AND survival rate AND healthcare disparities AND young adult* Found: 13 Yield: 0
		neoplasms AND survival rate AND health status disparities AND young adult* Found: 13 Yield: 1
oncology AND survival AND young adult* Found: 4 Yield: 0	oncology AND survival* AND young adult* Found: 1 Yield: 0	medical oncology AND survival rate AND young adult* Found: 15 Yield: 0
neoplasms AND health services accessibility AND young adult* Found: 45 Yield: 7	neoplasms AND health care access* AND young adult* Found: 8 Yield: 0	neoplasms AND health services accessibility AND ethnic groups AND young adult* Found: 36 Yield: 0
		neoplasms AND health services accessibility AND disabled persons AND young adult* Found: 3 Yield: 0
		neoplasms AND health services accessibility AND educational status AND young adult* Found: 7 Yield: 0

(continued) neoplasms AND health services accessibility AND young adult* Found: 45 Yield: 7	(continued) neoplasms AND health care access* AND young adult* Found: 8 Yield: 0	neoplasms AND health services accessibility AND rural health AND young adult* Found: 0 Yield: 0
		neoplasms AND health services accessibility AND urban health AND young adult* Found: 0 Yield: 0
		neoplasms AND health services accessibility AND socioeconomic factors AND young adult* Found: 76 Yield: 0
		neoplasms AND health services accessibility AND insurance AND young adult* Found: 27 Yield: 0
		neoplasms AND health services accessibility AND healthcare disparities AND young adult* Found: 40 Yield: 1
		neoplasms AND health services accessibility AND health status disparities AND young adult* Found: 13 Yield: 0
		oncology AND health services accessibility AND young adult* Found: 3 Yield: 0
neoplasms AND treatment delay AND young adult* Found: 1 Yield: 0	neoplasms AND treatment delay* AND young adult* Found: 2 Yield: 0	neoplasms AND treatment delay AND young adult* Found: 0 Yield: 0

oncology AND treatment delay AND young adult* Found: 0 Yield: 0	oncology AND treatment delay* AND young adult* Found: 0 Yield: 0	medical oncology AND treatment delay AND young adult* Found: 0 Yield: 0
neoplasms AND early detection of cancer AND young adult* Found: 25 Yield: 0	neoplasms AND early detection of cancer* AND young adult* Found: 5 Yield: 0	neoplasms AND early detection of cancer AND ethnic groups AND young adult* Found: 65 Yield: 1
		neoplasms AND early detection of cancer AND disabled persons AND young adult* Found: 4 Yield: 0
		neoplasms AND early detection of cancer AND educational status AND young adult* Found: 25 Yield: 0
		neoplasms AND early detection of cancer AND rural health AND young adult* Found: 3 Yield: 0
		neoplasms AND early detection of cancer AND urban health AND young adult* Found: 2 Yield: 0
		neoplasms AND early detection of cancer AND socioeconomic factors AND young adult* Found: 99 Yield: 0
		neoplasms AND early detection of cancer AND insurance AND young adult* Found: 14 Yield: 1

(continued) neoplasms AND early detection of cancer AND young adult* Found: 25 Yield: 0	(continued) neoplasms AND early detection of cancer* AND young adult* Found: 5 Yield: 0	neoplasms AND early detection of cancer AND healthcare disparities AND young adult* Found: 26 Yield: 0
		neoplasms AND early detection of cancer AND health status disparities AND young adult* Found: 7 Yield: 0
oncology AND early detection of cancer AND young adult* Found: 0 Yield: 0	oncology AND early detection of cancer* AND young adult* Found: 0 Yield: 0	medical oncology AND early detection of cancer AND young adult* Found: 1 Yield: 0
neoplasms AND neoplasm staging AND young adult* Found: 38 Yield: 2	neoplasms AND neoplasm staging* AND young adult* Found: 0 Yield: 0	neoplasms AND neoplasm staging AND ethnic groups AND young adult* Found: 65 Yield: 0
		neoplasms AND neoplasm staging AND disabled persons AND young adult* Found: 0 Yield: 0
		neoplasms AND neoplasm staging AND educational status AND young adult* Found: 16 Yield: 1
		neoplasms AND neoplasm staging AND rural health AND young adult* Found: 3 Yield: 0
		neoplasms AND neoplasm staging AND urban health AND young adult* Found: 1 Yield: 0

(continued) neoplasms AND neoplasm staging AND young adult* Found: 38 Yield: 2	(continued) neoplasms AND neoplasm staging* AND young adult* Found: 0 Yield: 0	neoplasms AND neoplasm staging AND socioeconomic factors AND young adult* Found: 84 Yield: 0
		neoplasms AND neoplasm staging AND insurance AND young adult* Found: 17 Yield: 1
		neoplasms AND neoplasm staging AND healthcare disparities AND young adult* Found: 26 Yield: 0
		neoplasms AND neoplasm staging AND health status disparities AND young adult* Found: 19 Yield: 0
oncology AND neoplasm staging AND young adult* Found: 7 Yield: 0	neoplasms AND neoplasm staging* AND young adult* Found: 0 Yield: 0	medical oncology AND neoplasm staging AND young adult* Found: 21 Yield: 0
neoplasms AND cancer screening AND young adult* Found: 14 Yield: 0	neoplasms AND cancer screening AND young adult* Found: 3 Yield: 0	neoplasms AND cancer screening**
oncology AND cancer screening AND young adult* Found: 0 Yield: 0	oncology AND cancer screening AND young adult* Found: 1 Yield: 0	medical oncology AND cancer screening**
neoplasms AND needs assessment AND young adult* Found: 36 Yield: 3	neoplasms AND needs assessment AND young adult* Found: 3 Yield: 0	neoplasms AND needs assessment AND ethnic groups AND young adult* Found: 7 Yield: 0

(continued) neoplasms AND needs assessment AND young adult* Found: 36 Yield: 0	(continued) neoplasms AND needs assessment AND young adult* Found: 3 Yield: 0	neoplasms AND needs assessment AND disabled persons AND young adult* Found: 0 Yield: 0
		neoplasms AND needs assessment AND educational status AND young adult* Found: 2 Yield: 0
		neoplasms AND needs assessment AND rural health Found: 0 Yield: 0
		neoplasms AND needs assessment AND urban health AND young adult* Found: 1 Yield: 0
		neoplasms AND needs assessment AND socioeconomic factors AND young adult* Found: 19 Yield: 0
		neoplasms AND needs assessment AND insurance AND young adult* Found: 7 Yield: 0
		neoplasms AND needs assessment AND healthcare disparities AND young adult* Found: 4 Yield: 0
		neoplasms AND needs assessment AND health status disparities AND young adult* Found: 2 Yield: 0

oncology AND needs assessment AND young adult* Found: 3 Yield: 0	oncology AND needs assessment AND young adult* Found: 0 Yield: 0	medical oncology AND needs assessment AND young adult* Found: 8 Yield: 0
neoplasms AND health services needs and demand AND young adult* Found: 46 Yield: 0	neoplasms AND health service needs AND young adult* Found: 6 Yield: 0	neoplasms AND health services needs and demand AND ethnic groups AND young adult* Found: 9 Yield: 0
		neoplasms AND health services needs and demand AND disabled persons AND young adult* Found: 1 Yield: 0
		neoplasms AND health services needs and demand AND educational status AND young adult* Found: 6 Yield: 0
		neoplasms AND health services needs and demand AND rural health AND young adult* Found: 0 Yield: 0
		neoplasms AND health services needs and demand AND urban health AND young adult* Found: 0 Yield: 0
		neoplasms AND health services needs and demand AND socioeconomic factors AND young adult* Found: 25 Yield: 0

(continued) neoplasms AND health services needs and demand AND young adult* Found: 46 Yield: 0	(continued) neoplasms AND health service needs AND young adult* Found: 6 Yield: 0	neoplasms AND health services needs and demand AND insurance AND young adult* Found: 9 Yield: 0
		neoplasms AND needs assessment AND healthcare disparities AND young adult* Found: 4 Yield: 0
		neoplasms AND needs assessment AND health status disparities AND young adult* Found: 4 Yield: 0
oncology AND health services needs and demand AND young adult* Found: 2 Yield: 0	oncology AND health service needs AND young adult* Found: 0 Yield: 0	medical oncology AND health services needs and demand AND young adult* Found: 9 Yield: 0

* Searched as a keyword rather than a MeSH term because the database did not have it or an equivalent as a MeSH term

** In OVID via PubMed, the MeSH term 'cancer screening' is captured under the MeSH term 'early detection of cancer'

Table 2

Key Terms by Database.

CINAHL via EBSCO	PsycINFO via EBSCO	Medline via PubMed
Neoplasms	Neoplasms	Neoplasms
Oncology	Oncology	Medical Oncology
Incidence	Incidence*	Incidence
Prevalence	Prevalence*	Prevalence
Mortality	Mortality rate	Mortality
Morbidity	Morbidity	Morbidity
Survival	Survival*	Survival Rate
Health services accessibility	Health care access*	Health services accessibility
Treatment delay	Treatment delay*	Treatment delay
Early detection of cancer	Early detection of cancer*	Early detection of cancer
Neoplasm staging	Neoplasm staging	Neoplasm staging
Cancer screening	Cancer screening	Early detection of cancer
Needs assessment	Needs assessment	Needs assessment
Health services needs	Health services needs	Health services needs and demand
Young adult*	Young adult*	Young adult*
		Ethnic group
		Disabled persons
		Educational status
		Rural health
		Urban health
		Socioeconomic factors
		Insurance
		Healthcare disparities
		Health status disparities

* Searched as a keyword rather than a MeSH term because the database did not have it or an equivalent as a MeSH term

Table 3

Quality Assessment of Included Studies.

	Authors	Objectives	Defined sample	Non-respondents	All variables	Data Analysis	Interaction	Sources of bias	Funding	Total
1	Aizer et al. (2014)	1	1	1	1	1	1	1	1	8
2	Albritton et al. (2007)	1	1	0	1	0	1	1	1	6
3	Brinton et al. (2008)	1	1	0	1	1	1	1	1	7
4	Chien et al. (2014)	1	1	1	1	0	0	1	1	6
5	Cowburn et al. (2013)	1	1	0	1	1	1	1	1	7
6	Denslow et al. (2012)	1	1	0	1	1	0	1	1	6
7	DeSantis et al. (2010)	1	1	0	1	1	0	1	1	6
8	Fedewa et al. (2012)	1	1	1	1	1	1	1	1	8
9	Gamba et al. (2013)	1	1	0	1	1	1	1	1	7
10	Grover et al. (2013)	1	1	1	1	1	0	1	1	7
11	Hausauer et al. (2011)	1	1	0	1	1	0	1	1	6
12	Henderson et al. (2013)	1	1	0	1	1	0	1	1	6
13	Holmes et al. (2008)	1	1	0	1	1	1	1	1	7

14	Howell et al. (2007)	1	1	0	1	1	0	1	1	6
15	Jemal et al. (2011)	1	1	0	1	1	1	1	1	7
16	Johnson et al. (2011)	1	1	0	1	1	1	1	0	6
17	Joslyn et al. (2005)	1	1	0	1	0	1	1	1	6
18	Keegan et al. (2012)	1	1	0	1	1	0	1	1	6
19	Keegan et al. (2014)	1	1	0	1	1	0	1	1	6
20	Kent et al. (2010)	1	1	0	1	1	1	1	1	7
21	Kent et al. (2009)	1	1	1	1	1	1	1	1	8
22	Kirchoff et al. (2012)	1	1	1	1	1	0	1	1	7
23	Letourneau et al. (2012)	1	1	1	1	1	0	1	1	7
24	Liu et al. (2013)	1	1	0	1	1	0	1	0	5
25	Martin et al. (2007)	1	1	0	1	1	0	1	1	6
26	McGlynn et al. (2005)	1	1	0	1	1	1	1	1	7
27	Merrill & Anderson (2011)	1	1	0	1	1	1	1	1	7
28	Parsons et al. (2011)	1	1	0	1	1	0	1	1	6
29	Richey et al (2006)	1	1	0	1	1	1	1	1	7

30	Robbins et al. (2014)	1	1	1	1	1	1	1	1	8
31	Roland et al. (2013)	1	1	0	1	1	0	1	1	6
32	Saraiya et al. (2009)	1	1	0	1	1	0	1	1	6
3	Scharpf et al. (2006)	1	1	1	1	1	1	1	0	7
34	Smith et al. (2012)	1	1	0	1	1	1	1	1	7
35	Tarone (2006)	1	1	0	1	1	1	0	0	5
36	Townsend et al. (2010)	1	1	1	1	1	1	1	1	8
37	Weir et al. (2011)	1	1	1	1	1	1	1	1	8
38	Wolfson et al. (2014)	1	1	0	1	1	0	1	1	6
39	Zebrack et al. (2013)	1	1	1	1	1	0	1	1	7
40	Zebrack (2008)	1	1	0	1	0	0	1	1	5
41	Zebrack (2009)	1	1	0	1	0	0	1	1	5
42	Zebrack et al. (2007)	1	1	0	1	0	0	1	1	5

Table 4

Article Summaries for Studies About Incidence and Mortality (Theme 1).

	Authors	Data Source, N	Ages	Cancer	Outcome	Relevant Findings	Raw Results
Age							
6	Denslow et al. (2012)	NCCR, n=3,652	19-98	Cervical	Incidence, mortality	Higher incidence and mortality among 30 – 39 y.o. as compared to 19 – 29 y.o.	30 – 39 y.o.: 21.5%; 786/3652 19 – 29 y.o.: 5.6%; 203/3562
13	Holmes et al. (2008)	SEER, n=16,580	15-49	Testicular	Incidence	Lowest incidence among 15–19 y.o., highest among 30-34 y.o.	30-34 y.o.: 8.1 per 100,000 in 2004 15-19 y.o.: 2.0 per 100,000 in 2004
21	Kent et al. (2009)	CCR, n=7,688	0-39	Leukemia	Mortality	Risk of death higher among 30-39 y.o. as compared to 15-29 y.o.	OS: 2.65 (15-29 y.o./0-14 y.o.); 2.91 (30-39 y.o./0-14 y.o.)
26	McGlynn et al. (2005)	SEER, n=NR	Not reported	Testicular	Incidence	Highest increase among 35 to 39 year olds Seminoma (subtype) rates highest among 35 to 39 years old.	No raw data reported
34	Smith et al. (2012)	CCR, n=7,343	15-40	Advanced Stage HL	Incidence	Highest incidence for advanced HL among 35-39 year olds as compared 15-19 year olds.	Adjusted OR: = 1.34 (35-39 y.o./15.19 y.o.)

37	Weir et al. (2011)	NPCR & SEER, n=41,715	15-39	Melanoma	Incidence	Incidence increased with age	<p>Males: 15-19 y.o.: 783/15,677; 20-24 y.o.: 1,539/15,677; 25-29 y.o.: 2,642/15,677; 30-34 y.o.: 4,223/15,677; 35-39 y.o.: 6,490/15,677)</p> <p>Females: 15-19 y.o.: 1,191/26,036; 20-24 y.o.: 3,318/26,036; 25-29 y.o.: 5,149/26,036; 30-34 y.o.: 7,185/26,036; 35-39 y.o.: 9,193/26,036)</p>
Race/ethnicity							
3	Brinton et al. (2008)	SEER, n=387,231	<30 - 50+	Breast	Incidence	Among 30-39, higher incidence among BL compared to W. Lowest incidence among AI/AN, API & HA.	<p>BL: 30-39 y.o.: 56.5/33,251</p> <p>W: 30-39 y.o.: 52.5/292,342</p>
4	Chien et al. (2014)	SEER, n=41,056	15-39	Testicular	Incidence	Higher annual percent change among HA-W males as compared to non-HA W males, across all stages	HA-W: rose 1.6-fold from 7.2 per 100,000 (1992) to 11.3 per 100,000 (2010) non-HA: plateau in incidence between 1992 and 2010
7	DeSantis et al. (2010)	NCDB & SEER, n=284,177	20-99	Breast	Incidence	Higher incidence among BL women as compared to W women, among 20-30 y.o.	<p>NCDB: White: 4.7%; n=169,486 Black: 8.9%; n=24,483</p> <p>SEER: White: 4.7%; n= 81,434 Black: 8.2%; n=8,774 total</p>

16	Johnson et al. (2011)	SEER, n=10,534	0-19	Extracranial Solid Tumors	Survival	Among 15-19 y.o., lowest survival for BL males.	All cancers: B/W: 1.31 (total), 1.61 (males), 1.01 (females) A/PI/W: 1.34 (total), 1.59 (males), 1.04 (females) Survival probabilities: W: 0.78; B:0.64; A/PI:0.71; AI/AN:0.80; Non-HA:0.77; HA:0.74
17	Joslyn et al. (2005)	NAACCR Breast Cancer Research Data Set, n=363,801	10-85+	Breast	Incidence	Higher incidence among BL women as compared to W women.	20-24: BL/W: 1.92; 25-29: BL/W: 1.56; API/W: 0.68; 30-34: BL/W: 1.31, API/W: 0.73; 35-59: BL/W: 1.18; AI/W: 0.37; API/W: 0.82
20	Kent et al. (2010)	CCR, n=3,762	15-39	Non-Hodgkin's Lymphoma	Survival	Lower survival associated with being BL and HA as compared to W.	Diagnosed at a distant state: Non-HA BL: 52% API: 34.7% Mortality: BL/W: 1.50, HA/W:1.30, API/W HR=0.86; unadjusted HR for lymphoma specific mortality: BL/W HR=1.38, HA/W HR=1.27, API/W HR = 1.35

24	Liu et al. (2013)	SEER, n=55,153	18-39	Breast	Incidence, stage at diagnosis, survival	Highest incidence among BL patients. Worst 5-year disease-specific survival among BL and API patients. Best 5-year overall survival among AsA patients, followed by W, BL and HA-W patients.	Disease specific: survival: BL: 71.8%; AsA: 84.6%; Filipino: 82.9%; Japanese: 86.0%; Chinese: 85.6%; Hawaiian/PI: 76.1%; Korean 89.3%; Asian Indian/Pakistani: 84.9%; Vietnamese: 85.6% Overall survival BL: 69.4%; W: 80.0%; HA W:77.0 AsA: 83.5%; Filipino: 81.1%; Japanese: 86.0%; Chinese: 84.8%; Hawaiian/PI: 74.6%; Korean: 88.3%; Asian Indian/Pakistani: 82.5% Vietnamese: 86.1%
27	Merrill & Anderson (2011)	SEER, n=NR	30-80+	Colon & Rectal	Incidence	Among 30 to 39 y.o., higher incidence among BL men and women as compared to W men and women.	IR per 100,00: W: 6.6 (men); 5.6 BL: 7.4 (men); 7.2 (women)
29	Richey et al (2006)	SEER, n=NR	<20 - 45+	Nasopharyngeal Carcinoma	Incidence	Among 20-29 y.o., highest incidence among AsA, then B and W.	IR per 1,000,000 Asian/other: 7.18; BL: 1.87; W: .96
30	Robbins et al. (2014)	NCDB, n=285,448	15-39	All	Stage at diagnosis	Highest risk of distant stage diagnosis among BL, followed by HA and API, as compared to W.	B/W: 1.35 (males), 1.45 (females) HA/W: 1.17 (males), 1.12 (females) API/W: 1.31 (males), 1.30 (females)

37	Weir et al. (2011)	NPCR & SEER, n=41,715	15-39	Melanoma	Incidence	Highest incidence among white patients followed AI/AN, HA-W, API and BL. Regional and distant stage diagnosis occurs more often in HA-W and non-W as compared to W patients.	W: 14,191 (males), 23,321 (females) HA-W: 392 (males), 853 (females) BL: 79 (males); 125 (females) AI/AN: 53 (males), 74 (females) API: 64 (males), 117 (females)
Combination of Age and Race/ethnicity*							
17	Joslyn et al. (2005)	NAACCR Breast Cancer Research Data Set, n=363,801	10-85+	Breast	Incidence	Among 20-24 y.o., highest rate among BL as compared to W. Among 25-34 y.o, highest rate among B, followed by W and API. Among 35-39, highest rate among BL, followed by W, API and AI/AN. Among 20-24, higher rate among HA as compared to non-HA. Among 25-29, 30-34, and 35-39 higher incidence among non-HA as compared to HA.	Among 20 – 24 y.o.: BL: 2.30, W: 1.20; Among 25 – 29 y.o.: BL: 12.20, API: 5.29, W: 7.81; Among 30 – 34 y.o.: BL: 33.21, API: 18.54, W: 25.38; Among 35 – 39 y.o.: BL: 68.50, AI/AN: 21.76, API: 47.74, W: 58.20

35	Tarone (2006)	SEER, n=NR	20-49	Breast	Incidence	Among 20-29 y.o., change in incidence rate per year higher among BL women as compared to W women. Among 30-39, change in breast cancer incidence rate per year higher among W women as compared to BL women.	Among 20-29 y.o.: In Situ Cancer Slope W: .009, BL: .029 Invasive Cancer Slope W: -.022 BL: -.001 Age Group: 30-39 y.o.: In Situ Cancer Slope W: .25, BL: .15 Invasive Cancer Slope W: -.24, BL: -.52
26	McGlynn et al. (2005)	SEER, n=NR	NR	Testicular	Incidence	Nonseminoma (subtype) rates peaked at age 20 to 24 years among W men and 25 to 29 among BL men.	No raw data reported

36	Townsend et al. (2010)	SEER, n=40,354	0-65+	Testicular	Incidence	<p>Seminoma (subtype) rates peak for AI/AN men at 20 to 24, for HA and API men at age 30 to 34, for W men at age 35 to 39, and for BL men at age 30 to 39.</p> <p>Nonseminoma (subtype) rates peak at 20 to 24 for HA, AI/AN and API men and at 25 to 29 for W and BL men.</p>	<p>IR per 100,000</p> <p>Seminoma</p> <p>BL: (30-34 yo): 1.9</p> <p>HA (30-34 y.o.): 5.3</p> <p>APIs (30-34 y.o.): 2.2</p> <p>W (35-39 y.o.): 10.4</p> <p>AI/AN (25-29 y.o.): 6.2</p> <p>Nonseminoma Rates:</p> <p>HA (20-24 y.o.): 5.9</p> <p>AIAN: (20-24 y.o.): 5.3</p> <p>API (20-24 y.o.): 1.8</p> <p>W: (25-29 y.o.): 7.9</p> <p>BL (25-29 yo): 1.3</p>
34	Smith et al. (2012)	CCR, n=7,343	15-40	Advanced Stage HL	Incidence	<p>Among males 15 to 24, highest incidence among HA and BL.</p> <p>Among males, 25 to 34 and 35 to 39, higher incidence among HA. Among females, 35 to 39 higher incidence among HA</p>	<p>15-25 y.o.: BL: 54%</p> <p>25-34 y.o.: H: 46%</p> <p>35-39 y.o.: H: 53%</p>

Gender

9	Gamba et al. (2013)	SEER, n=26,107	15-39	Melanoma	Incidence, mortality	Incidence higher among females 15-29 years old, and higher among males 35-39 years old. Disease-specific death higher for males as compared to females.	Females 15-24 y.o.: 16.2% 25-29 y.o.: 20.3% 30-34 y.o.: 27.1% 35-39 y.o.: 36.5% Males: 15-24 y.o.: 13.2% 25-29 y.o.: 17.5% 30-34 y.o.: 27.1% 35-39 y.o.: 42.2% Number of deaths: males: 993 females: 568
15	Jemal et al. (2011)	SEER, n=85,865	15-65+	Melanoma	Incidence, mortality	Among 15-39 year olds, incidence higher among females as compared to males. Higher mortality among males as compared to females.	IR per 100,000: females: 16.5 males: 9.7 Mortality: females: .5 males: 37
22	Kirchoff et al. (2012)	BRFSS, n=979	20-39	All cancers	Prevalence	More female cancer survivors reported having more than 1 type of cancer as compared to male	Females: 9.8% Males: 3.0%
34	Smith et al. (2012)	CCR, n=7,343	15-40	Advanced Stage HL	Incidence	Higher OR for advanced HL among males as compared to females	Adjusted OR: male/female: 1.57

37	Weir et al. (2011)	NPCR & SEER, n=41,715	15-39	Melanoma	Incidence	Incidence higher among females as compared to males. Males more likely to be diagnosed with regional and distant disease as compared to females.	IR: Females: 9.74 Males: 5.77 Regional & Distant Disease: Females: W: 1.14, HA: .33, B/API/AI/AN: .14 Males: W: 1.18, HA: .21, BL/API/AI/AN: .13
Insurance Status							
1	Aizer et al. (2014)	SEER, n=39, 447	20 - 40	All	Incidence, mortality	Insurance associated with lower presence of metastatic disease and mortality, even after adjusting for demographic factors	Incidence for insured/uninsured: univariable OR: .56 multivariable OR: .84 All-cause mortality for insured/uninsured: univariable HR: .43 multivariable HR: .77
8	Fedewa et al. (2012)	NCDB, n=69,739,	21 - 85	Cervical	Stage at diagnosis	Lowest incidence of advanced stage disease 21 to 34 with private insurance	Privately insured: 13.31% Medicare: 23.02% Medicaid: 23.07% Uninsured: 20.82%
20	Kent et al. (2010)	CCR, n=3,762	15-39	NHL	Survival	Lower survival associated public insurance as compared to no insurance.	Adjusted HR all cause, no insurance as reference: Government: 1.32 Managed or private: 0.82 Unknown: .96 Disease specific: Government: 1.24 Managed or private: .96 Unknown: .89

30	Robbins et al. (2014)	NCDB, n=285,448	15-39	All	Incidence, stage at diagnosis	Higher incidence risk of melanoma and skin carcinomas, thyroid carcinoma, carcinoma of the breast, and carcinoma of the genitourinary tract higher among uninsured. Lower incidence risk among uninsured for carcinoma of the trachea, bronchus, and lung; carcinoma of other and ill-defined sites. Risk estimates similar for those with Medicaid, Medicare and uninsured patients. Uninsured patients as compared to insured patients, more likely to be diagnosed with distant stage and less likely to be diagnosed with local stage.	Distant Stage RR, private insurance as reference: Melanoma & Skin: Uninsured: 1.46 Medicaid: 6.22 Medicare: 3.03 Thyroid: Uninsured: 1.61 Medicaid: 1.33 Medicare: 1.60 Breast: Uninsured: 2.12 Medicaid: 2.15 Medicare: 2.02 Genitourinary Tract: Uninsured: 1.82 Medicaid: 1.66 Medicare: 1.05 Trachea, bronchus, and lung: Uninsured: 1.23 Medicaid: 1.21 Medicare: 1.15 Other and ill-defined sites: Uninsured: 1.42 Medicaid: 1.39 Medicare: .61
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34	Smith et al. (2012)	CCR, n=7,343	15-40	Advanced Stage HL	Incidence	Lower incidence among those with private insurance as compared to those without insurance.	Adjusted OR: no insurance/private insurance: 1.76, public insurance/private insurance: 1.45
Neighborhood SES							
11	Hausauer et al. (2011)	CCR, n=3,842	15-39	Melanoma	Incidence	Higher incidence associated with higher nSES quintile	Low: 1.23 Low-Intermediate: 1.14 Intermediate: 1.30 High-Intermediate: 1.33 High: 1.28
20	Kent et al. (2010)	CCR, n=3,762	15-39	NHL	Survival	Lower survival associated with lower nSES,	Unadjusted HR all cause: Lowest nSES/highest: 1.97. Unadjusted HR disease specific: Lowest nSES/highest: 1.70
34	Smith et al. (2012)	CCR, n=7,343	15-40	Advanced Stage HL	Incidence	Higher incidence associated with lower nSES.	Adjusted OR: 1 st quintile/5 th quintile: 1.47 2 nd quintile/5 th quintile: 1.22 3 rd quintile/5 th quintile: 1.20
United States Region							
30	Robbins et al. (2014)	NCDB, n=285,448	15-39	All	Stage at diagnosis	Slightly higher risk of distant stage among men treated in the Midwest, South and West as compared to Northeast. Slightly higher risk for females in the West.	Distant stage RR, Northeast as reference Males: Midwest: 1.05 South: 1.04 West: 1.07 Females: Midwest: 1.02 South: 1.01 West: 1.13
Marital Status							

20	Kent et al. (2010)	CCR, n=3,762	15-39	NHL	Survival	Higher survival associated with being married.	Adjusted HR all cause: 0.67, as compared to those who were single, separated, divorced, or widowed at diagnosis.
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* Articles summarized under the sub-header 'Combination of Age and Race/Ethnicity' are organized by cancer type, rather than in alphabetical order.

Key of abbreviations: AI/AN = American Indian/Alaskan Native; API = Asian/Pacific Islander; AsA = Asian; BL = Black; BRFSS = Behavioral Risk Factor Surveillance System; CCR = California Cancer Registry; ER = Estrogen Receptive; HA = Hispanic; NCDB = National Cancer Database; HL = Hodgkin's lymphoma; NAACCR = North American Association of Central Cancer Registries; NCCR = North Carolina Cancer Registry; NHL = Non-Hodgkin's lymphoma; NPCR = National Program of Cancer Registries; NR = not reported; nSES = Neighborhood SES; PR = Progesterone Receptive; SEER = Surveillance Epidemiology and End Results; SES = socioeconomic status; W = White; y.o. = year old

Table 5

Article Summaries for Studies About Access to Care (Theme 2).

	Authors	Data Source, N	Ages	Cancer	Relevant Findings	Raw Results
Having Insurance						
1	Aizer et al. (2014)	SEER, n=39,447	20 - 40	All	Being uninsured was associated with being younger, not white, unmarried and from areas of lower income, lower education levels and rural as compared to insured individuals.	Uninsured: Male: 50% Median age: 33 H. S. Edu: 79% Income: \$46,000 Non-white: 55.28% Rural: 14% Insured: Male: 33% Median age: 35 HS Edu: 82% Income: \$49,000 Non-white: 37.99% Rural: 9%
22	Kirchoff et al. (2012)	BRFSS, n=979	20-39	All	Female cancer survivors more likely to be uninsured as compared to non-survivors. Overall, similar rates of being insured among BL, W and other races.	Avoided care: Male survivors: 22% Controls: 12% Uninsured: Female survivors: 35% Controls: 18%

30	Robbins et al. (2014)	NCDB, n=285,448	15-39	All	Uninsured patients were more likely to be younger, male, BL or HA, live in the South, live in ZIP code with the lowest median income and highest percentages of resident without a high school diploma, receive treatment in teaching hospitals and less likely to be treated in NCI-designated facilities.	Uninsured: Males: 1.51 Females: 1.86 20-24 y.o. Males: 0.95 Females: 0.78 BL: Males: 1.35 Females: 1.45 HA: Males: 1.17 Females: 1.12 South: Males: 1.04 Females: 1.01 ZIP Code-based median income < \$30,000: Males: 1.04 Females: 1.02 W/o HS diploma: Males: 1.09 Females: 1.12 Treatment in teaching hospitals: Males: 1.09 Females: 1.05 NCI-designated: Males: 1.23 Females: 1.24
34	Smith et al. (2012)	CCR, n=7,343	15-40	Advanced Stage HL	Males were more likely to without insurance as compared to females.	Without insurance or self-pay: Male: 65% Female: 35%
Time to Diagnosis and Treatment						

25	Martin et al. (2007)	MDACC Tumor Registry, n=235	15-29	Leukemia, HL, NHL, sarcoma, brain tumors, thyroid	Patients with public insurance experienced longer delays in receiving a diagnosis than private or self-pay patients. No differences by age, gender, race, ethnicity, marital status, or zip code of residence.	<p>Days to diagnosis:</p> <p>Leukemia: Private: 14 Public: 52</p> <p>HL: Private: 68 Public: 70</p> <p>NHL: Private: 68 Public: 66</p> <p>Sarcoma: Private: 124 Public: 209</p> <p>Brain Tumors: Private: 90 Public: 143</p> <p>Thyroid: Private: 159 Public: 216</p>
28	Parsons et al. (2011)	National Cancer Institute Patterns of Care Study & SEER, n=1,358	15-39	NHL, HL, GCC, ALL or sarcoma*	Excluding germ cell cancers, median time to treatment did not differ between men and women. Higher rates of BL and API patients had 2-month lag for first treatment, as compared to other races.	<p>BL: Median: 12 0 days: 20.7% 1-14 days: 26.4% 15-30 days: 16.5% 31-60 days: 14.9% >60 days: 10.7%</p> <p>API: Median: 8 0 days: 32.0% 1-14 days: 27.6% 15-30 days: 13.4% 31-60 days: 12.0% >60 days: 8.8%</p>

Clinical Trial Participation

28	Parsons et al. (2011)	National Cancer Institute Patterns of Care Study & SEER, n=1,358	15-39	NHL, HL, GCC, ALL or sarcoma*	Higher clinical trial participation among those 15-19 as compared to 35-39, among non-HA BL as compared to non-HA W, among those with Medicaid or private insurance as compared to HMO and uninsured.	Clinical Trial 15-19 y.o.: 34.3% 35-39 y.o.: 3.7% Non HA BL: 11.2 Non HA W: 8.9% Private insurance: 13.9% Medicaid: 14.1% Managed care: 7.3% Uninsured: 3.2%
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Receiving Definitive Therapy

1	Aizer et al. (2014)	SEER, n=39,447	20 - 40	All	Receiving definitive therapy associated with having insurance, even after adjusting for demographic factors.	Adjusted OR, insurance/no insurance: 2.68
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Treated at an NCI-designated, Children Oncology Group Institution or a American College of Surgeons cancer center

2	Albritton et al. (2007)	UCR, n=1,355	0 - 24	All	Less than 1% 19 to 24 year olds and only 34% of 15-19 year olds treated at PCMC. 13% of 15-19 year-olds and 21% of 20-24 year-olds were never seen at ACS sites. Non-W patients seen more often at PCMC as compared to W patients. Among 15 to 19 years olds, those that live farthest away were seen at PCMC less often.	Seen at PCMC: Non-W: 57.9% W: 45.8% Distance to PCMC: <25 miles: 37.6% 25-49.9 miles: 28.4% 50-99 miles: 36.84% 100+ miles: 9; 37; 24.3%
14	Howell et al. (2007)	GCCR, n=1,751	0-19	All	Of the 15-19 y.o., only 36% were treated at a COG institution	15-19 y.o.: 36%

38	Wolfson et al. (2014)	LACR, n=784	0-39	CNS Tumors	Those 22 to 29 were less likely to be treated at an NCI-CCC/COG site as compared to those 15 to 21. Among those 22-39, public or no insurance, low SES and living more than 5 miles from the closest NCI-CCC was associated with less likely to receive care at an NCI-CCC.	Receiving care at NCI-CCC/COG: 15-21 y.o.: 60.4% 22-39 y.o. 16.7%
Receiving Ongoing Medical Care						
19	Keegan et al. (2014)	AYA HOPE study, n=465	15-39	NHL, HL, GCC, ALL or sarcoma*	Those without insurance were less likely to go to the doctor. High cost/no insurance identified as top reason for not going to a doctor's visit. Among those who had no cancer-related visit, higher portion were male, BL or AI/AN and HA, unemployed and had no health insurance.	Go to doctors: Uninsured: 82% Insurance: 97% No cancer related visit in previous 12 months: Male: 71.8% BL & AI/AN: 14.0% HA: 29.8% Unemployed: 19.3% No health insurance currently & last year: 17.5%
Cancer-related Fertility Counseling						
23	Letourneau et al. (2012)	Invited participants from CCR, n=1,041	18-40	Leukemia, HL, NHL, breast, gastrointestinal	More likely to receive counseling associated with higher age at diagnosis, desire for children, and education level. Those with lower income were less likely to receive counseling. Trend towards decreased access HA as compared to W women. No fertility preservation reported by the AA and non-heterosexual women.	Adjusted odds ratio: Diagnosed at 36-40 y.o.: .6 Desire for children: 1.2 Education Level Bachelor's or higher: 1.4 no bachelor's degree: .7 Income <\$30,000: .7 HA: .9
Cervical Cancer Screening Rates						

5	Cowburn et al. (2013)	Electronic Health Records from 17 community health centers in Oregon and California, n=11,560	21-64	None	Among W 21-39 y.o, more likely to get a pap test if continuously insured as compared to those partially insured. Among HA 21-39 y.o, uninsured more likely to receive a pap test than those partially or fully insured.	Uninsured/continuously insured among W females, PR: 1.08 Partially insured/continuously insured, HA females, PR: .91; Uninsured/continuously insured among , HA females: 1.11
12	Henderson et al. (2013)	NSFG, n=7,856	15-29	None	Higher percentage of 18 to 20 y.o. women screened too early as compared to other ages. Missed screening highest among HA women and foreign-born women. A gap or no health insurance in previous 12 months was associated with less guideline-consistent screenings.	Screened too early: 18-20 y.o.: 24.1% 15-17 y.o: 9.1% Missed screening: BL: 14.2% W: 18.3% HA: 22.2% Foreign born: 30.1% US born: 17.5
31	Roland et al. (2013)	NHIS, n=2,198	18-29	None	Mean age of first Pap test younger for BL and older for HA and AsA as compared to W. Younger for those with less than a high school education as compared to those with a college degree. Usual source of healthcare and use of birth control associated with a pap test within the previous 12 months.	Mean age of first pap test: HA: 18.1 y.o. BL: 16.9 y.o. AsA: 19.8 y.o. W: 17.4 y.o. <high school ed: 16.9 ≥ College degree: 18.5 Use of healthcare, OR: 1.64 Current use of birth control, OR: 2.31

32	Saraiya et al. (2009)	NSFG, n=2,513	15-24	None	HA women were less likely to have a pap test in previous 12 months, as compared to W and BL women.	W: 16.7% BL: 14.6% HA: 4.4%
Cervical Cancer Treatment Modalities						
10	Grover et al. (2013)	SEER, n=6,586	15-39	Cervical	W women more likely to have a hysterectomy as compared to non-W women. Receiving radiotherapy as a primary treatment was associated with having a higher stage cancer, being widowed or single, and not being W.	Hysterectomy: W: 93.26% BL/other: 86.48% Stage: IA2 OR: 3.09 IB OR: 21.41 Widowed/single OR: 1.39 Nonwhite, OR: 1.95
Mammography Rates						
33	Scharpf et al. (2006)	BRFSS, n=354,097	18-40	None	Higher mammography rates for BL women between the ages of 18 and 33 as compared to W women. After 33, rates are similar between BL and W women.	BL: 18-23 y.o.: 20% 30-33 y.o.: 25.7% W: 18-23 y.o.: 11%; 30-33 y.o.: 18.1%

* Specifically Ewing's sarcoma, osteosarcoma and rhabdomyosarcoma

Key of abbreviations: ACS = American College of Surgeons; AI/AN = American Indian/Alaskan Native; ALL = Acute lymphocytic leukemia; API = Asian/Pacific Islander; AsA = Asian; BL = Black; BRFSS = Behavioral Risk Factor Surveillance System; CCR = California Cancer Registry; COG = Children's Oncology Group; CNS = Central Nervous System; GCC = Germ cell cancer; GCCR = Georgia Comprehensive Cancer Registry; HA = Hispanic; HL = Hodgkin's lymphoma; LACR = Los Angeles cancer registry, MDACC = University of Texas M.D. Anderson Cancer Center; NAACCR = North American Association of Central Cancer Registries; NCI-CCC = National Cancer Institute Comprehensive Cancer Center; NCDB = National Cancer Database; NHIS = National Health Interview Survey; NHL = Non-Hodgkin lymphoma; NPCR = National Program of Cancer Registries; NR = not reported; nSES = Neighborhood SES; NSFG = National Survey of Family Growth, PCMC = Primarily Children's Medical Center; SEER = Surveillance Epidemiology and End Results; SES = socioeconomic status; UCR = Utah Cancer Registry; W = White; y.o. = years old

Table 6

Article Summaries for Studies About Unmet Supportive Care Needs (Theme 3).

	Authors	Data Source, N	Ages	Cancer	Outcome	Relevant Findings	Raw Results
	Age						
19	Keegan et al. (2012)	AYA HOPE, n=523	15-39	NHL, HL, GCC, ALL or sarcoma*	Survey – information and service needs	Those 30 to 39 reported more unmet needs related to treatments, possible long terms side effects, financial support for care and concern about getting another type of cancer as compared to those 15 to 19.	Handling concern about getting another type of cancer, 30-39 as reference: 15-19 y.o.: 0.67 20-29 y.o.: 0.91 How to check signs that cancer has returned: 15-19 y.o.: 0.66 20-29 y.o.: 0.93 New treatment options: 15-19 y.o.: 0.33 20-29 y.o.: 0.80 Complementary and alt. tx: 15-19 y.o.: 0.18 20-29 y.o.: 0.45 Possible long term side effects of cancer treatment 15-19 y.o.: 0.45 20-29 y.o.: 0.84 Financial support for medical care: 15-19 y.o.: 0.31 20-29 y.o.: 0.67 Concern about getting another type of cancer: 15-19 y.o.: 0.42

	(continued) Keegan et al. (2012)						20-29 y.o.: 0.69 6 or more unmet info. needs: 15-19 y.o.: 0.49 20-29 y.o.: 0.90 Any unmet service needs: 15-19 y.o.: 0.71 20-29 y.o.: 1.08
40	Zebrack (2008)	Online survey, n=217	18-40	All except brain tumors & thyroid	Survey - Information and service care needs survey	Those 18-29 reported a greater need for infertility information, infertility treatment/services, and adoption services as compared to 30-40.	Infertility info: 18-29 y.o.: 37.9% 30-40 y.o.: 23.6% Infertility treatment/services: 18-29 y.o.: 40% 30-40 y.o.: 18% Adoption Services: 18-29 y.o.: 47.7% 30-40 y.o.: 32.6%
42	Zebrack et al. (2007)	Online survey, n=1,088	15-35	All	Survey - health and supportive care needs	Younger patients reported greater need for fertility services, scheduling treatments that fit their lifestyles and support from friends and family. Older patients reported more needs for state-of-the-art treatment, access to multiple medical opinions, greater responsibility for one's own health care and decision-making. Among those off treatment, younger	Spearman rank correlations with age, for patients in treatment: State of the art treatment: .13 Reducing side effects: -.08 Fertility services: -.08 Access to multiple opinions: .11 Scheduling: -.15 Support from family: -.12 Support from friends: -.12 Assuming responsibility: .10 Patients off treatment: Healthcare providers: .07 Information about fertility: .06

	(continued) Zebrack et al. (2007)					reported greater need for information and counseling around fertility, reproductive problems and options for having children, need for support from friends and engagement in social activities. Older reported higher needs for counseling and support to help manage distress, providers who know about long-term follow-up care for survivors, and survivor support groups.	Encourage for social activities: -.09 Counseling services: .10
39	Zebrack et al. (2013)	3 pediatric cancer centers, 2 adult cancer centers, n=208	14-39	Any invasive cancer	Survey - Service use and unmet needs	Those 20 to 29 and 30 to 39 (as compared to 14 to 19), reported a greater unmet need for information, age-appropriate internet sites for education and support, mental counseling, religious/spiritual counseling, counseling for a family member, transportation and CAM services. Those 20-29, most likely to report an unmet need for	Cancer Information: 14-19 y.o.: 10.3% 20-29 y.o.: 28.3% 30-39 y.o.: 23.1% Age-App. Internet sites for edu and support: 14-19 y.o.: 24.7% 20-29 y.o.: 47.8% 30-39 y.o.: 49.2% Mental Health counseling: 14-19 y.o.: 13.4% 20-29 y.o.: 32.6% 30-39 y.o.: 38.5% Religious/Spiritual counseling: 14-19 y.o.: 4.1%

	(continued) Zebrack et al. (2013)					information about cancer, infertility and diet/nutrition and CAM services. Those 30-39 reported the greatest need for family counseling and assistance with insurance, disability and Social Security benefits.	20-29 y.o.: 6.5% 30-39 y.o.: 21.5% Family Counseling: 14-19 y.o.: 14.4% 20-29 y.o.: 19.6% 30-39 y.o.: 44.6%
41	Zebrack (2009)	Online survey, n=879	18-39	All except brain tumors & thyroid	Survey - Information and service care needs	Higher unmet need for information about cancer, assistance with health insurance, mental health counseling, infertility information and treatment, contemporary and alternative medicine, camps or retreats among younger survivors (at current age). Higher unmet need for child care among older survivors (at current age)	Info about cancer: 18-29 y.o.: 11.6% 30-40 y.o.: 6.0% Assistance w/ health insurance 18-29 y.o.: 33.2% 30-40 y.o.: (23.6% Mental health counseling: 18-29 y.o.: 27.7 30-40 y.o.: 21.5% Alcohol or drug counseling: 18-29 y.o.: 3.8% 30-40 y.o.: 1.4% Infertility info: 18-29 y.o.: 41.6% 30-40 y.o.: 21.2% Infertility treatment: 18-29 y.o.: 31.6% 30-40 y.o.: 19.3% CAM: 18-29 y.o.: 35.6 30-40 y.o.: 28.9 Camps/retreats:

	(continued) Zebrack (2009)						18-29 y.o.: 52.2% 30-40 y.o.: 43.9% Child care: 18-29 y.o.: 5.6% 30-40 y.o.: 11.3%
Race/Ethnicity							
19	Keegan et al. (2012)	AYA HOPE, n=523	15-39	NHL, HL, GCC, ALL or sarcoma*	Survey – information and service needs	BL, AI/AN or HA reported more unmet needs related to recurrence, treatment, and financial support as compared to W and more likely to report more than 6 unmet information needs.	<p>Odds ratio</p> <p>Handling concern about cancer returning, W as reference: BL & AI/AN: 2.19 HA: 1.51</p> <p>How to check signs that cancer has returned: BL & AI/AN: 2.36 HA: 2.47</p> <p>New tx for your cancer: BL & AI/AN: 2.37 HA: 1.84</p> <p>CAM treatment: BL & AI/AN: 2.50 HA: 1.79</p> <p>Possible long term side effects of cancer tx BL & AI/AN: 1.38 HA: 0.66</p> <p>Financial support for medical care: BL & AI/AN: 4.78 HA: 1.79</p> <p>Concern about getting another type of cancer: BL & AI/AN: 1.62</p>

	(continued) Keegan et al. (2012)						HA: 1.10 6 or more unmet info. needs: BL & AI/AN: 2.58 HA: 1.81 Any unmet service needs: BL & AI/AN: 1.43 HA: 1.17
40	Zebrack (2008)	Online survey, n=217	18-40	All except brain tumors & thyroid	Survey - Information and service care needs survey	Higher need for family counseling among non- W, as compared to W.	W: 19.4 Non-W: 42.0
41	Zebrack (2009)	Online survey, n=879	18-39	All except brain tumors & thyroid	Survey - Information and service care needs	Higher unmet need for internet sites, diet and nutrition information, exercise information, mental health counseling, family counseling, counseling related to sexuality, infertility information, CAM services, and transportation assistance among non-W, as compared to W	Internet sites: W: 29.3% Non-W: 37.8% Diet and nutrition info W: 39.4% Non-W: 51.7% Exercise info: W: 40.3% Non-W: 55.1% Mental health counseling: W: 22.7% Non-W: 31.5% Family counseling: W: 19.4% Non-W: 42.0% Counseling related to sexuality: W: 28% Non-W: 44.4% Infertility info: W: 28.0% Non-W: 40.0%

	(continued) Zebrack (2009)						CAM: W: 30.4% Non-W: 42.2% Transportation assistance: White: 9.2% Non-W: 24.7%
39	Zebrack et al. (2013)	3 pediatric & 2 adult cancer centers, n=208	14-39	Any invasive cancer	Survey - Service use and unmet needs	Higher unmet need for cancer and fertility information non-W, as compared to W.	OR, non-W as reference Cancer information: .33 Fertility information: .31 Family counseling: 4.26
Gender							
19	Keegan et al. (2012)	AYA HOPE, n=523	15-39	NHL, HL, GCC, ALL or sarcoma*	Survey – information and service needs	More unmet information needs among males, as compared to females, and males were more likely to report more than 6 unmet information needs.	Odds ratio for male as compared to female Handling concern about cancer returning: 1.67 How to check signs that cancer has returned: 1.49 New tx for your cancer: 1.68 CAM: 1.83 Possible long term side effects of cancer tx: .57 Financial support for medical care: 1.52 Concern about getting another type of cancer: 1.56 6 or more unmet info. needs: 1.66 Any unmet service needs: 1.35
41	Zebrack (2009)	Online survey, n=879	18-39	All except brain	Survey - Information and	Higher unmet need for counseling related to sexuality, infertility	Counseling related to sexuality: Female: 33.1%

	(continued) Zebrack (2009)			tumors & thyroid	service care needs	information, adoption services, and camps/retreats among females as compared to males. Higher unmet need for alcohol or drug counseling and transportation assistance among males as compared to females.	Male: 21.4% Alcohol or drug counseling: Female: 1.7% Male: 3.9 Infertility info: Female: 31.1 Male: 25.0% Adoption services: Female: 33.0% Male: 23.6% Camps/retreats: Female: 50.2% Male: 38.5% Transportation assistance: Female: 9.1% Male: 15.3%
42	Zebrack et al. (2007)	Online survey, n=1,088	15-35	All	Survey - health and supportive care needs	Higher need for minimizing side effects, age-appropriate information about cancer, opportunities to meet other people with cancer, and psychological counseling among females. Higher need for support from friends, multiple medical opinions and responsibility for one's own health higher among males as compared to females.	No raw results reported

39	Zebrack et al. (2013)	3 pediatric cancer centers, 2 adult cancer centers, n=208	14-39	Any invasive cancer	Survey - Service use and unmet needs	Higher unmet need for counseling related to sexuality and intimacy among males. Higher unmet need for religious counseling among females as compared to males.	Odds ratio, male as reference Sexuality, intimacy counseling: 0.20 Religious, spiritual counseling: 3.26
Employment Status							
41	Zebrack (2009)	Online survey, n=879	18-39	All except brain tumors & thyroid	Survey - Information and service care needs	Higher unmet need for information about cancer, exercise information, mental health counseling, family counseling, counseling related to sexuality, and transportation assistance among those unemployed as compared to those employed.	Info about cancer: Employed: 7.9% Unemployed: 13.4% Exercise info: Employed: 41.3% Unemployed: 52.4% Mental health counseling: Employed: 23.0% Unemployed: 32.1% Family counseling: Employed: 161 (20.6) Unemployed: 28 (34.6) Counseling related to sexuality: Employed: 223 (28.6) Unemployed: 36 (44.4)
Education Level							
40	Zebrack (2008)	Online survey, n=217	18-40	All except brain tumors & thyroid	Survey - Information and service care needs survey	Higher need for internet site among those without a college degree as compared to those with a college degree.	Internet site: With college degree: 19.5% W/o college degree: 33%

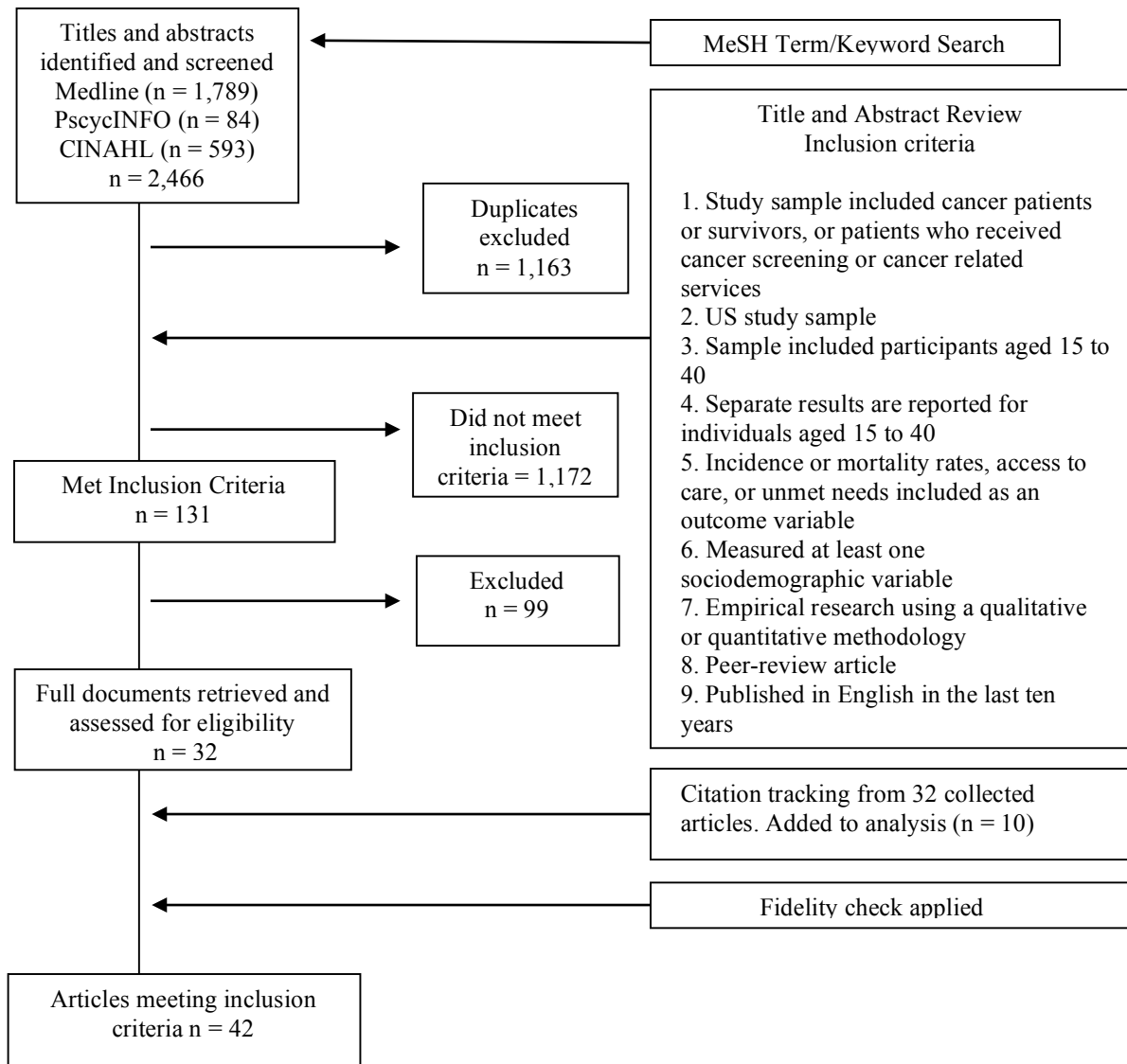
41	Zebrack (2009)	Online survey, n=879	18-39	All except brain tumors & thyroid	Survey - Information and service care needs	Higher unmet need for information about cancer, internet sites, diet and nutrition information, exercise information, mental health counseling, religious/spiritual counseling, alcohol or drug counseling, CAM services, transportation assistance and child care among those with less than a college degree as compared to those with a college degree.	<p>Info about cancer: <College grad: 10.7% College grad: 7.4%</p> <p>Internet sites: <College grad: 37.6% College grad: 26.0%</p> <p>Diet and nutrition info: <College grad: 47.8% College grad: 37.2%</p> <p>Exercise info: <College grad: 49.5% College grad: 38.5%</p> <p>Mental health counseling: <College grad: 29.3% College grad: 20.9%</p> <p>Religious/spiritual counseling: <College grad: 17.8% College grad: 11.8%</p> <p>Alcohol or drug counseling: <College grad: 4.0% College grad: %1.4%</p> <p>CAM: <College grad: 36.4% College grad: 28.8%</p> <p>Transportation assistance: <College grad: 14.5% College grad: 8.9%</p> <p>Child care: <College grad: 11.4% College grad: 7.7%</p>
Marital Status							

40	Zebrack (2008)	Online survey, n=217	18-40	All except brain tumors & thyroid	Survey - Information and service care needs survey	Higher need for infertility treatment among those unmarried as compared to those married.	Married: 20.9% Unmarried: 28.9%
41	Zebrack (2009)	Online survey, n=879	18-39	All except brain tumors & thyroid	Survey - Information and service care needs	Higher unmet need for information about cancer, internet sites, religious/spiritual counseling, alcohol or drug counseling, infertility information, infertility services, camps/retreats, transportation assistance as those unmarried as compared to those married. Higher need for diet and nutrition information, and child care among those not married, as compared to those married.	Info about cancer: Married: 6.8% Not married: 10.9% Internet sites: Married: 27.7% Not married: 35.5% Diet and nutrition info: Married: 44.7% Not married: 35.2% Religious/spiritual counseling: Married: 12.0% Not married: 16.6% Alcohol or drug counseling: Married: 1.2% Not married: 4.0% Infertility info: Married: 25.1% Not married: 35.5% Infertility services: Married: 20.9% Not married: 28.9% Camps/retreats: Married: 43.9% Not married: 51.4% Transportation assistance: Married: 8.5% Not married: 14.3%

* Specifically Ewing's sarcoma, osteosarcoma and rhabdomyosarcoma

Key abbreviations: ALL = Acute lymphocytic leukemia; BL = Black; GCC = Germ cell cancer; HA = Hispanic; HL = Hodgkin's lymphoma; NHL = Non-Hodgkin lymphoma; tx = treatment; W = White

Figure 1. Flow chart of included articles for review.



CHAPTER 3: DISTRESS AND COPING AMONG AYA ONCOLOGY PATIENTS AND THEIR CAREGIVERS: A REVIEW OF THE LITERATURE

Introduction

Adolescent and Young Adult (AYA) Oncology patients (ages 15 - 39) are a unique cancer population due to stagnant survival rates as compared to younger and older patients (Bleyer & Barr, 2009; Bleyer et al., 2009; Soliman & Agresta, 2008) and complex psychosocial needs (Dyson, Thompson, Palmer, Thomas, & Schofield, 2012; Keegan et al., 2012; Smith et al., 2013; Zebrack et al., 2013; Zebrack et al., 2014). In 2006, the National Cancer Institute (NCI) formed an AYA Oncology Progress Review Group (AYAO PRG) who compiled a report identifying the barriers and challenges faced by AYAs and provided recommendations for improving their cancer care (AYAO PRG, 2006). Recommendations from the AYAO PRG included: (a) identifying how cancer is unique among AYA oncology patients, (b) increasing education and training to improve care for AYAs, (c) creating tools specific for AYA cancer patients, (d) improving prevention, screening, diagnosis, treatment, survivorship and end of life care to AYAs across the cancer continuum, and (e) promoting advocacy and support of AYA cancer patients (AYAO PRG, 2006). Despite the progress made since 2006 (Nass & Patlak, 2013), and the growth of AYA-specific programs (Reed et al., 2014), ongoing efforts to improve the quality of care to AYAs are needed (Nass & Patlak, 2013) as AYAs continue to report unmet health and supportive care needs (Nass & Patlak, 2013; Zebrack et al., 2013; Zebrack et al., 2014).

AYA oncology patients are confronted with the challenges of treatment while also attending to typical developmental tasks associated with emerging adulthood, such as exploring education and career opportunities, gaining independence from their families of origin, and

building new relationships, including with partners, friends and other parts of their support system (Arnett, 2000, 2003). Cancer-related issues such as premature confrontation with mortality, changes in physical appearance, increased dependence on parents, disruptions in social life and school/employment because of treatment and health-related concerns may be particularly distressing for AYAs (Kwak et al., 2013a; Kwak et al., 2013b; Zebrack, 2011; Zebrack et al., 2014). Providers and support persons who take care of AYAs aim to support treatment demands while also attending to normal developmental tasks of emerging adulthood (Grinyer, 2008; Miedema, Hamilton, & Easley, 2007), which may be related to their own distress (Girgis et al., 2013; Northouse et al., 2012; Stenberg et al., 2010). The National Comprehensive Cancer Network (NCCN) defines distress as a “multifactorial unpleasant emotional experience of a psychological, social and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment” (NCCN, 2014, p. 3). Bultz and Carlson (2005) identified psychological distress as the “sixth vital sign in cancer care” (Bultz & Carlson, 2005, p. 6440). Clinically significant emotional distress places AYA patients at risk for poor adherence to therapy and thus lowered potential for survival (Butow et al., 2010).

Cancer, and its related distress, is discussed as a shared experience between patients and their caregivers (Badr et al., 2011; Davis-Ali, Chesler, & Chesney, 1993; Manne, Badr, Zaider, Nelson, & Kissane, 2010; Traa et al., 2015). The systemic transactional model (Bodenmann, 1995, 2005) argues that shared stressors, such as cancer, are best viewed through a lens that acknowledges how stress and coping are interrelated among individuals in close relationships, such as a patient-caregiver dyad. As AYAs face the challenges of cancer, patients’ relationships with their caregivers, which can include parents, spouses and friends, are an important source of support for coping and adjusting to the illness experience (Stenberg et al., 2010; Woodgate,

2006). However, research about the shared experience of cancer between AYAs and their caregivers remains sparse. Only one study to date has explored the shared experience of distress among AYAs and their parental caregivers (Juth et al., 2015). However, Juth et al's (2015) sample was limited to parental caregivers of AYAs aged 12 to 24. In general, research about the experiences of caregivers of AYAs with cancer is mostly limited to parental caregivers of patients ranging in age from 11 to 24 years of age (Barling, Stevens, & Davis, 2013; Grinyer, 2006, 2008, 2009; Lewis, Mooney-Somers, Jordens, & Kerridge, 2014). While the experiences of non-parental AYA caregivers are studied, they are often combined in studies that include a large age range study sample (e.g., 16-85; Lambert, Jones, Girgis, & Lecathelinais, 2012), limiting one's ability to generalize the findings beyond the combined population and isolate the experiences of non-parental caregivers of AYA patients. Thus, the purpose of this literature review is to: (a) present the theories of emerging adulthood (Arnett, 2000, 2003) and the systemic transactional model (Bodenmann, 1995, 2005) as the theoretical foundation for understanding distress and coping among AYAs and their caregivers, (b) review the literature on distress and coping among AYA cancer patients and survivors, caregivers of cancer patients, and cancer patient-caregiver dyads, and (c) discuss potential areas of growth for ongoing improvement of care to AYA oncology patients and their caregivers.

Theoretical Foundation

The theoretical foundation for this literature review is guided by two theories: (a) the theory of emerging adulthood (Arnett, 2000, 2003), and (b) the systemic transactional model (STM; Bodenmann, 1995, 2005). The theory of emerging adulthood (Arnett, 2000, 2003) presents a lens through which to understand some of the developmental challenges that AYAs experience, particularly among those between the ages of 18 through 30. While many researchers

have examined the impact of cancer on the individual AYA patient, very few have considered the impact of cancer on the AYA's relational system and vice versa (Grinyer, 2008; Juth et al., 2015). STM posits that when a dyad (i.e., a patient and her or his caregiver) is faced with a shared stressor (i.e., cancer), partners within the dyad will cope with it individually and interdependently (Bodenmann, 1995, 2005). STM (Bodenmann, 1995, 2005) provides a framework for examining the interdependence of distress and coping among the AYA patient-caregiver dyad. The theory of emerging adulthood as it relates to the AYA with cancer will be discussed first, followed by STM.

The Theory of Emerging Adulthood

The period between 18 and 30 years of age is a stage of development, entitled *Emerging Adulthood* (Arnett, 2000, 2003). It is identified as a unique developmental stage that occurs between adolescence and adulthood (Arnett, 2000, 2003). While the development stage of emerging adulthood does not account for the entire NCI-designated AYA age range (15 to 39), it does provide a valuable framework for considering the challenges patients face as they transition from adolescence and into adulthood with some meeting normative milestones sooner or later in age (e.g., launching, graduating school, partnering). Emerging adulthood is characterized as the most transitory phase of life as individuals explore life and identity formation, which includes negotiating and navigating relationships with family and friends. Emerging adults, as discussed by Arnett (2000, 2003, 2007), tend to have a wider scope of possible activities than persons in other age periods because they are less likely to be constrained by role requirements.

During this stage of development, according to the theory of emerging adulthood, individuals are in the midst of navigating and negotiating their relationships with their families of origin while further developing their support systems (Arnett, 2007). While during adolescence,

individuals are heavily connected with their parents, those transitioning toward adulthood start to develop a sense of autonomy from their parents and rely more on the influence of their friends, romantic partners, and co-workers as they shift towards developing their own families (Arnett, 2007). The transition to adulthood can be a time of great stress and may overwhelm individuals' ability to adapt to stressors, such as cancer. For AYAs with cancer, there is the potential to experience a dual crisis in having to deal with complex normative developmental tasks of emerging adulthood, as well as cancer-related stressors (Thomas, Seymour, Brien, Sawyer, & Ashley, 2006; Zebrack, 2011).

A cancer diagnosis impacts all aspects of life for AYAs including daily activities, energy levels, physical appearance, relationships, school engagement, psychosocial function, work responsibilities, view of the future, sexuality and fertility (Albritton & Bleyer, 2003; Eiser & Kuperberg, 2007; Grinyer, 2002, 2003; Kyngäs et al., 2001; Zebrack, Hamilton, & Smith, 2009; Zebrack, 2011). Studies on AYA cancer patients' needs suggested that psychosocial and information needs are among the most prevalent unmet needs (Dyson et al., 2012; Palmer, Mitchell, Thompson, & Sexton, 2007; Smith et al., 2013; Thompson, Palmer, & Dyson, 2009; Zebrack, Bleyer, Albritton, Medearis, & Tang, 2006; Zebrack et al., 2013, 2014; Zebrack, Mills, & Weitzman, 2007; Zebrack, 2008, 2009), supporting the view that cancer impacts multiple aspects of AYA patients' lives. This includes the need for support from family and friends, mental health and family therapy, meeting other young people with cancer, and age-appropriate information, services, and internet sites. The theory of emerging adulthood (Arnett, 2000) as discussed here provides a foundation for understanding why AYA patients are developmentally complex. STM, as discussed in the proceeding section, provides a framework for understanding

the interconnectedness of coping and distress among dyads, such as the AYA cancer patient-caregiver dyad.

Systemic Transactional Model

Early views on stress and coping focused on individual processes (Lazarus, 1966; Lazarus & Folkman, 1984) and failed to consider the interpersonal nature of stress and coping. Stress and coping is an interactive process between two individuals, typically discussed in the literature within the context of couples (e.g., Badr, Carmack, Kashy, Cristofanilli, & Revenson, 2011; Bodenmann, Meuwly, & Kayser, 2011; Lim, Shon, Paek, & Daly, 2014; Milbury, Badr, Fossella, Pisters, & Carmack, 2013; Rottmann et al., 2015) but can include any dyad (e.g., mother-daughter, father-son, siblings, roommates, cohabiting individuals, a business partnership). Stress can be experienced within any dyad in multiple ways, including: (a) stress that only impacts one partner, (b) stress that directly impacts one partner and indirectly the other, and (c) stress that impacts both partners (Bodenmann, 1995, 2005).

Expanding on intraindividually-oriented theories such as the transactional model of coping (Lazarus, 1966; Lazarus & Folkman, 1984), the systemic transactional model (STM) views stressors as dyadic if they affect both partners of the dyad directly or indirectly (Bodenmann, 1995, 2005). Cancer is an example of a dyadic stressor because it has the potential to directly and indirectly impact the patient and those closest to the patient such as the patient's caregiver. STM posits that when a dyad, such as the patient-caregiver dyad, is faced with a shared stressor, the pair cope both individually and jointly (Bodenmann, 1995, 2005). The dyadic coping process is initiated when a partner communicates her or his stress to the other in hopes of receiving support from the other (Bodenmann, 1995, 2005). The other partner may respond in

either a supportive or unsupportive way, while simultaneously attempting to manage her or his own stress at the individual level (Bodenmann, 1995, 2005).

Bodenmann (1995, 2005) broadly differentiated between positive and negative dyadic coping. He defined positive coping as supportive, delegated or common, and negative dyadic coping as support that is distancing, insincere, or criticizing (Bodenmann, 1995, 2005).

Supportive dyadic coping involves one partner assisting the other in her or his coping efforts, which can include empathic understanding and providing practical advice (Bodenmann, 1995, 2005). Delegated dyadic coping involves one partner taking over the responsibilities of the other to reduce that individual's stress (Bodenmann, 1995, 2005). Common dyadic coping involves the dyad working together through joint problem solving, information seeking, or relaxing together (Bodenmann, 1995, 2005). The different ways that a dyad copes with a particular stressor is likely to influence each partner's perceived stress and distress levels (Traa et al., 2015).

STM applies a theoretical framework for understanding dyadic coping, relationship quality, and distress among dyads facing cancer (e.g., Badr et al., 2011; Manne, Badr, Zaider, Nelson, & Kissane, 2010; Traa et al., 2015). While researchers found a weak relationship between positive dyadic coping and dyadic distress (Badr et al., 2010; Hinnen, Ranchor, Baas, Sanderman, & Hagedoorn, 2009), they reported positive dyadic coping was associated with better relationship functioning (Traa et al., 2015), higher relationship quality (Bodenmann, Pihet, & Kayser, 2006) and overall better dyadic adjustment to cancer (Badr et al., 2010; Badr & Carmack Taylor, 2008; Berg et al., 2008; Lafaye et al., 2014; Manne et al., 2010). In contrast, negative dyadic coping behaviors, such as criticism or avoidance, are negatively associated with distress among dyads facing cancer (Badr et al., 2010; Feldman & Broussard, 2006; Manne et al.,

2010). Before discussing the empirical literature related to dyadic distress and coping, a review of the literature on distress among AYAs and then distress among caregivers is presented.

Distress among AYAs

Researchers reported that between 6% and 56% of AYA cancer patients experienced clinically significant levels of distress depending on the study's sample size, age range of the samples, timing of data collection, and measurement tool (Dyson et al., 2012; Hedström, Ljungman, & von Essen, 2005; Kwak et al., 2013a; Zabora, Brintzenhofesoc, Curbow, Hooker, & Piantadosi, 2001; Zebrack et al., 2014). AYA patients may experience distress due to a variety of reasons including physical side-effects, altered body image, limited participation in normal activities such as school and work or social activities, feelings of isolation, hopeless, and anxiety, as well as changes in family and friend dynamics (Abrams, Hazen, & Penson, 2007; Ameringer, Serlin, Hughes, Friedrich, & Ward, 2006; Evan, Kaufman, Cook, & Zeltzer, 2006; Evan & Zeltzer, 2006; Hilton, Emslie, Hunt, Chapple, & Ziebland, 2009; Jones, 2008; Soliman & Agresta, 2008). Researchers reported greater distress among AYA cancer patients among who were female, non-White, in treatment and experiencing greater treatment side effects, unemployed, and who had unmet physical and daily living needs (Dyson et al., 2012; Enskär & von Essen, 2007; Hedström et al., 2005; Kwak et al., 2013a; Yanez, Garcia, Victorson, & Salsman, 2013; Zebrack et al., 2014).

AYA patients with higher distress levels also reported higher levels of unmet needs for individual mental health and family therapy (Zebrack et al., 2014). The unmet need for individual and family therapy may be related to AYAs' process of renegotiating relationships during cancer treatment. For some AYAs, cancer requires that patients become more dependent on parents after periods of independence (Albritton & Bleyer, 2003; Zebrack, 2011; Zebrack &

Isaacson, 2012). For those patients who are married or in committed relationships, they become dependent on a partner in a way that the couple may not be ready (Stenberg et al., 2010). This change from independence to dependence may be an additional source of stress during a time already known for being stressful. In addition to distress, coping styles and support from family and friends may be related to patients' overall psychosocial functioning (Decker, 2007; Evan & Zeltzer, 2006; Zebrack, 2011).

Coping Strategies

AYA cancer patients cope in diverse ways with their illness (Decker, Haase, & Bell, 2007; Miedema et al., 2007), including the use of emotion- and problem-focused coping (Kyngäs et al., 2001; Miedema et al., 2007; Snöbohm & Heiwe, 2013), as well as, negative expression and support-seeking coping (Trevino et al., 2012). Emotion- and problem-focused coping included making meaning of their illness, adapting to being sick, seeking professional help, seeking help from family and friends, trying to regain control, reflectivity, eating properly, and being physically active (Kyngas et al., 2001; Miedema et al., 2007; Snöbohm & Heiwe, 2013). Use of emotion- and problem-focused coping strategies is associated with better adjustment among young adults with cancer (Miedema et al., 2007; Kyngas et al., 2001; Snöbohm & Heiwe, 2013). Trevino and colleagues (2012) reported negative expression coping strategies such as denial, self-blaming and venting was associated with increased grief, while seeking support was associated with higher levels of anxiety. Kyngas and colleagues (2001) concluded that AYAs' use of coping strategies occurred within the context of their relationships with friends and family. Proponents of STM support these findings and help to explain the gap between patients, families, and friends' coping by theorizing that coping occurs both individually and jointly (Bodenmann, 2005).

Importance of Support from Family and Friends

AYA oncology patients reported that relationships with family and friends are important sources of support during their cancer experiences (e.g., Bellizzi et al., 2012; Carpentier & Fortenberry, 2010; Decker, 2007; Enskär & von Essen, 2007; Goodall, King, Ewing, Smith, & Kenny, 2012; Miedema et al., 2007; Zebrack, 2011; Zebrack et al., 2006). Having a broad support system enabled effective coping and psychological well-being to emerge (Miedema et al., 2007; Trevino, Fasciano, Block, & Prigerson, 2012). AYAs valued talking to family and friends about cancer and non-cancer related issues (Hilton et al., 2009; Miedema et al., 2007; Trevino et al., 2012). Having someone to talk to may be even more important to AYAs' overall psychological well-being than receiving tangible support (Trevino et al., 2012).

Researchers identified support from family as an important contributor to positive adjustment among AYAs with cancer (Decker, 2007; Synder & Pearse, 2010). Family members provide valuable emotional, informational, and experiential support by being available to patients to talk about their fears, concerns, treatment-related issues, and talking about others' experiences with cancer (Coyne, Wollin, & Creedy, 2012; Synder & Pearse, 2010). Young women (ages 36-45) reported that family was supportive when they were just present, acted as a buffer from society, and were flexible with changing roles (Coyne et al., 2012). Families also provided valuable tangible support by taking patients to medical appointments, assisting with daily living activities, and taking care of household responsibilities (Synder & Pearse, 2010). All of this support is valuable for patients to manage the distress associated with cancer and its' treatment (Coyne et al., 2012; Evan & Zeltzer, 2006; Grinyer, 2003). Some AYA patients, particularly those over the age of 30, reported family support to be more important to their adjustment than professional support (Synder & Pearse, 2010).

Support from friends also served an important role in AYAs' ability to manage cancer (Cassano, Nagel, & O'Mara, 2008; Zebrack et al., 2006). The teenage years and early 20s are marked as a time when individuals place greater emphasis on friendships as compared to family relationships (Arnett, Ramos, & Jensen, 2001; Arnett, 2007), which may explain why peers are an important source of support for AYAs. Some AYAs with cancer reported peer relationships to be as important (Synder & Pearse, 2010; Woodgate, 2006; Zebrack, Chesler, & Kaplan, 2010), if not more important (Cassano et al., 2008; Zebrack et al., 2006) than family support. AYAs' friends provided patients a sense of normalcy (Barling et al., 2013; Miedema et al., 2007; Snöbohm & Heiwe, 2013; Zebrack et al., 2010), by engaging with them in non-cancer related activities such as watching movies, playing games and spending times with friends (Decker, 2007; Goodall et al., 2012). Peers who have gone through cancer were also important because they understood some of the challenges that patients went through and helped normalize those experiences (Cassano et al., 2008; Woodgate, 2006).

However, family and friends were also a source of distress for some AYA oncology patients, particular those family and friends who are emotionally unavailable or need to be shielded from bad news (Hilton et al., 2009; Miedema, Easley, & Robinson, 2013; Synder & Pearse, 2010; Zebrack et al., 2010). There were times throughout patients' treatment that caregivers, such as parents, did not agree with patients' decisions about treatment and non-treatment related activities (e.g., spending time out of the house, traveling, not following all treatment recommendations), which led to additional distress for patients and caregivers (Grinyer, 2009).

While the psychosocial needs of AYAs has gained significant attention in the literature since the 2006 AYAO PRG report (Bleyer, O'Leary, Barr, & Ries, 2006; Ferrari et al., 2010;

Zebrack & Isaacson, 2012), and several AYA-specific programs developed in response to it (Reed et al., 2014), AYAs continue to report distress and unmet needs for psychosocial support, specifically as it relates to information, emotional and practical support (Zebrack et al., 2013, 2014). Many of the stressors that AYA patients reported recently are relational (e.g., limited participation in normal activities such as school and work or social activities, feelings of isolation, hopeless and anxiety and changes in family and friend dynamics), yet a shift toward a relational approach to understanding AYAs has not emerged. In order to capture the full image of distress among AYAs with cancer, it is also important to understand the impact of cancer on the caregivers of patients.

Cancer Caregivers

With the transition of cancer treatment from inpatient settings to outpatient clinics, a large portion of patient care shifted from healthcare professionals to the families, friends, and support systems of patients (Tangka et al., 2010; van Ryn et al., 2011). Researchers reported that the caregivers of cancer patients varied and included parents, children, spouses or partners, friends, siblings, or other family members (Adams, Boulton, & Watson, 2009; Applebaum & Breitbart, 2013; Bevans & Sternberg, 2012; Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008; Northouse, Katapodi, Schafenacker, & Weiss, 2012). Patients reported that their relationships with their caregivers were the most important relationships when faced with cancer (Coyne, Wollin, & Creedy, 2012; Hagedoorn, Buunk, Kuijer, Wobbes, & Sanderman, 2000; Zebrack, Mills, & Weitzman, 2007). Patients consistently relied on these individuals for emotional, informational, and tangible support (Synder & Pearse, 2010).

AYA Cancer Caregivers

The only estimation of who the caregivers of AYAs are was reported recently during a LIVESTRONG and Institute of Medicine workshop (Nass & Patlak, 2013). It was reported that based on an online survey done by LIVESTRONG, 82 percent of AYAs identified their parents as their primary caregivers (Nass & Patlak, 2013). However, it was not clear from the report what the age range of the sample was, so it is plausible that the sample did not include the entire NCI-designated age range (ages 15 to 39) for AYAs. As well, other sociodemographic variables about their participants such as marital status and current living arrangement were not reported. If the sample included a younger mean age, it is possible that unmarried participants who lived with their parents and/or had not transitioned fully into their adult roles skewed the studies' findings.

Empirical studies about the caregiving experiences of AYAs with cancer are mostly limited to parental caregivers of patients aged 11 to 24 years old (Barling et al., 2013; Grinyer, 2002, 2006, 2009; Lewis et al., 2014). These parental caregivers experienced distress, isolation, and decrements in their own physical and emotional health (Barling et al., 2013; Grinyer, 2006). These parents also discussed the challenges of providing care, while managing the household and other children (Barling et al., 2013; Grinyer, 2006). However, some parents reported that taking care of their young adult child strengthened their relationship (Barling et al., 2013).

Non-parental caregivers (e.g., spouses, partners, friends) of AYAs are often included in studies with a large age range study sample (e.g., 16-85; Lambert et al., 2012). Including non-parental caregivers of AYA oncology patients in larger studies provides insight about the overall effects of caregiving on individuals (Bigatti, Wagner, Lydon-Lam, Steiner, & Miller, 2011; Lambert, Girgis, Lecathelinais, & Stacey, 2013; Lambert et al., 2012; Mellon, Northouse, &

Weiss, 2006). However, these researchers reported no specific findings for caregivers of AYA patients, such as how caring for an AYA impacts the caregiver and how it may be similar or different than caring for a patient of a different age. As very few researchers to date have examined AYA distress or caregiver burden, findings from the general adult oncology literature provide some insights into caregiver distress.

Distress Among Caregivers

In the general adult oncology literature, spouses are typically reported as the primary caregiver (Applebaum & Breitbart, 2013; Bevans & Sternberg, 2012; Feldman & Broussard, 2006; Milbury et al., 2013). However, parents and adult children of patients also fulfill the caregiver role for some patients (Hagedoorn, Kreichbergs, & Appel, 2011; Romito, Goldzweig, Cormio, Hagedoorn, & Andersen, 2013). Caregivers reported multiple decrements in physical and psychosocial health (Girgis et al., 2013; Northouse et al., 2012; Stenberg et al., 2010). Caregivers reported symptoms including greater frequency of headaches, fatigue, sleep troubles, back, neck and shoulder problems, digestion problems and stress-related illnesses (Girgis et al., 2013). Caregivers experienced higher rates of anxiety and depression as compared to non-caregivers (Lambert et al., 2013; Mellon et al., 2006).

Caregiver distress may be related to type of care provided, the patient's symptoms, physical health and distress levels, the type of relationship, and caregiving burden (Applebaum & Breitbart, 2013; Dumont et al., 2006; Fujinami et al., 2014; Hodges, Humphris, & Macfarlane, 2005; Li et al., 2013; Northouse et al., 2012; Sharpe, Butow, Smith, McConnell, & Clarke, 2005; Stenberg, Cvancarova, Ekstedt, Olsson, & Ruland, 2014). As well, researchers found caregiver distress associated with being a woman, younger age, being a spousal caregiver, lower socioeconomic status, being employed, and lacking social support (Dumont et al., 2006;

Hagedoorn et al., 2008; Lund, Ross, Petersen, & Groenvold, 2014; Northouse et al., 2012; Romito et al., 2013; Williams, Tisch, Dixon, & McCorkle, 2013). Levels of distress among caregivers varied with time since initiating caregiving (Murray et al., 2010; Northouse et al., 2012) and higher caregiver burden (Fujinami et al., 2014; Milbury et al., 2013; Wagner et al., 2010).

Caregiver Burden

Distress and quality of life among caregivers of adult patients appears to be associated with caregiver burden (Fujinami et al., 2014; Girgis et al., 2013; Kim & Given, 2008; Lund et al., 2014; Northouse et al., 2012; Turkoglu & Kılıc, 2012). Caregivers provided emotional, practical, financial and medical support, including providing transportation and accompaniment to medical appointments, coordination of multiple healthcare settings, administration of medications, assistance with activities of daily livings, housework and helping to manage patients' emotional distress (Girgis et al., 2013; Li et al., 2013; Romito et al., 2013; Yabroff & Kim, 2009). Yabroff and Kim (2009) reported that caregivers spent on average 8.3 hours a day over the course of 12 to 17 months providing care for their loved ones, with significant variation across different types of cancers and stages of disease. Caregivers with less education and a lower family income reported spending more time caregiving as compared to those with more education and a higher income (Yabroff & Kim, 2009).

It is important to note that Stenberg and colleagues (2010) reported caregivers' perceived burden was not directly related to the number of caregiving hours but rather was based more on the subjective experience of being a caregiver and the availability of additional support. Furthermore, caregivers' own confidence in their role was associated with the severity of the patient's symptoms, other family responsibilities, availability of additional support, unmet needs,

and the quality of their relationship with the patient (Barling et al., 2013; Deatrick et al., 2014; Lund et al., 2014; Northouse et al., 2012; Sharpe et al., 2005). Researchers uncovered higher perceived caregiver burden associated with being female, being older, having a lower income, being unemployed, and having less education (Lambert et al., 2012; Sharpe et al., 2005; Turkoglu & Kılıc, 2012). The distress that patients and caregivers experienced is not independent, but rather reflects an interpersonal process through which both members of the dyad cope with cancer.

Distress Among Cancer Patient-Caregiver Dyads

According to the systemic transactional model (STM) of stress and coping (Bodenmann, 1995, 2005), the cancer patient and her or his caregiver influence each other in the adjustment process. There is evidence to suggest that the psychological distress of cancer survivors and their partners are interdependent (Gregorio et al., 2012; Juth et al., 2015; Kim & Given, 2008; Segrin, Badger, Dorros, Meek, & Lopez, 2007). While caregivers of adult cancer patients include spouses/partners, parents, adult children and others, a large portion of studies that examined dyadic distress are limited to couples (Baucom et al., 2012; Dorros, Card, Segrin, & Badger, 2010; Hagedoorn et al., 2008), rather than examining distress among other types of dyads, such as siblings or friends.

Couples faced with cancer experienced increased levels of distress due to the practical and emotional effects of cancer (Hagedoorn et al., 2008; Milbury et al., 2013; Segrin & Badger, 2014) that appear to be similar between patients and their partners (Dorros et al., 2010; Haun et al., 2014; Hodges et al., 2005; Hodgkinson et al., 2007; Segrin & Badger, 2014). Higher levels of dyadic distress (i.e., distress experienced by both the patient and the caregiver) were associated with higher levels of unmet needs, presence of anxiety or depression, relationship dissatisfaction

or low quality, lack of family support and caregiving burden (Baider et al., 2008; Baucom et al., 2012; Milbury et al., 2013; Segrin & Badger, 2014). However, it is important to note that females, whether they are the patient or the caregiver, experienced higher levels of distress as compared to their male counterparts (Hagedoorn et al., 2008; Hinnen et al., 2009; Hodges et al., 2005; Northouse et al., 2012). This finding aligns with the broader literature on gender differences in emotional expression among men and women (Notarius & Johnson, 1982; Zakowski et al., 2003). Women's emotional well-being is more affected by the well-being of others as compared to men's emotional well-being (Notarius & Johnson, 1982; Zakowski et al., 2003). Some caregivers experienced greater levels of distress than the patient (Hagedoorn et al., 2008; Hodges et al., 2005).

While these findings are important for a general understanding of dyadic distress among couples with cancer, these findings may not directly translate to AYA cancer patient-caregiver dyads. Emerging adulthood is a unique developmental stage in which interpersonal relationships are rapidly changing (Arnett, 2000), which may impact who serves as a caregiver for the AYA. Due to the transitory nature of emerging adulthood, the shared experience of cancer between AYAs and their caregivers may be quite different from pediatric or adult oncology populations.

Distress Among AYA Cancer Patient-Caregivers Dyads

To date, only Juth and colleagues (2015) studied the shared experience of cancer among AYA patients and their caregivers through a dyadic research design; however, they focused only on parental caregivers of patients between the ages of 12 and 24. They found AYA patients reported similar levels of stress as their parental caregivers. The dyad's perceived severity of the illness strongly influenced stress among AYA patients and their caregivers. Juth and colleagues' (2015) study provided a preliminary understanding of the dyadic nature of stress among AYA

patients and their caregivers and highlighted the need for more dyadic studies with the AYA oncology patient population. While these findings are similar to what is reported in the general adult oncology literature, additional studies with non-parental caregivers would provide greater insight and apply less assumptions regarding stress and coping among AYAs and their caregivers. As no known studies to date have examined the experience of dyadic coping among AYA oncology patient-caregivers dyads, findings from the general adult oncology literature provide insight about the dyadic nature of coping among patients and their caregivers when faced with cancer.

Dyadic Coping

As described by STM, in the face of a dyadic stressor, such as cancer, patients and their caregivers are likely to cope both individually and interdependently (Bodenmann, 2005). Depending on individual and dyadic appraisals of the stressor, dyads use various supportive or positive and unsupportive or negative dyadic coping strategies. Positive dyadic coping strategies include joint problem solving, negotiating daily tasks, relaxing together as well as being emotionally engaged with each other. Negative dyadic coping strategies include avoidance, withdrawal and criticism.

Adult oncology researchers noted that positive dyadic coping is associated with better dyadic adjustment (Badr et al., 2010; Badr & Carmack Taylor, 2008; Manne et al., 2010), improved quality of life, reductions in symptoms of anxiety and depression (Lafaye et al., 2014), and increased mood (Berg et al., 2008) among patients and their spousal caregivers. Patients and their spousal caregivers reported better dyadic adjustment with increased presence of assurance, communication of positivity, openness among the dyad, use of a social network and sharing of tasks among the patient-spousal caregiver dyad (Badr & Carmack Taylor, 2008). Positive dyadic

coping strategies that included jointly addressing each other's emotions was also associated with better dyadic adjustment (Badr et al., 2010) and higher relationship quality between patients and their spousal caregivers (Bodenmann, 2005; Rottmann et al., 2015). The use of problem-focused coping and social support seeking was associated with higher quality of life and lower levels of anxiety and depression among patient-spousal caregivers (Lafaye et al., 2014). While positive dyadic coping was not directly associated with the dyad's distress (Feldman & Broussard, 2006; Manne et al., 2010; Traa et al., 2015), one research team reported that resilience mediates the relationship between positive dyadic coping and decreased dyadic distress (Lim et al., 2014). Additional research is needed to better understand the relationship between distress and coping among patients and their caregivers.

Negative dyadic coping strategies were associated with increased dyadic distress levels and poorer dyadic adjustment among cancer patients and their spousal caregivers (Badr et al., 2010; Feldman & Broussard, 2006; Lafaye et al., 2014; Manne et al., 2010; Rottmann et al., 2015). Among patients and their spousal caregivers, negative coping strategies were associated with lower relationship quality (Rottman et al., 2015). Relationship quality may play an important role in the dyads' levels of distress and coping strategies and needs to be further investigated.

These findings from the general adult oncology literature provide support for the interconnectedness of distress and coping among cancer patients and their caregivers. However, many of these studies only included heterosexual patient and spousal caregiver dyads, limiting the generalizability of these findings to other dyad forms (e.g., mother-son, friend-friend, husband-husband). As well, most of the studies included older populations whose experiences may not be representative of AYA patients' and their caregivers' experiences.

Discussion

Recognized as a unique cancer population by the National Cancer Institute, with the help of the AYA O PRG in the mid-2000s, AYA oncology patients continue to experience stagnant survival rates (Bleyer & Barr, 2009; Bleyer et al., 2009) and complex unmet health and supportive care needs (Kent et al., 2013; Smith et al., 2013; Yanez et al., 2013; Zebrack et al., 2013, 2014). AYA oncology patients are confronted with the challenges of treatment while also attending to the tasks typical of the developmental stage of emerging adulthood (Arnett, 2000, 2003). AYA patients reported distress due to a variety of reasons including physical side-effects, altered body image, limited participation in normal activities such as school and work or social activities, feelings of isolation, hopeless, and anxiety, as well as changes in family and friend dynamics (Abrams, Hazen, & Penson, 2007; Ameringer, Serlin, Hughes, Friedrich, & Ward, 2006; Evan, Kaufman, Cook, & Zeltzer, 2006; Evan & Zeltzer, 2006; Hilton, Emslie, Hunt, Chapple, & Ziebland, 2009; Jones, 2008; Soliman & Agresta, 2008).

As AYAs face the challenges of cancer and normal developmental tasks, relationships with their caregivers serve as an important source of support for coping and adjusting to cancer (Stenberg et al., 2010; Woodgate, 2006). With patients relying more on caregivers for emotional, practical, financial and medical support (Girgis et al., 2013; Li et al., 2013; Romito et al., 2013; Yabroff & Kim, 2009), cancer evolves into a shared stressor between the patient and the caregiver (Davis-Ali et al., 1993; Juth et al., 2015). As posited by the systemic transactional model, when faced with a shared stressor, such as cancer, both members of the dyad are involved in an interrelated process of coping and distress (Bodenmann, 1995, 2005).

The framework of STM has been applied in the general adult oncology literature; however, is typically limited to heterosexual patient-spousal caregiver dyads (Baucom et al.,

2012; Dorros et al., 2010; Hagedoorn et al., 2008). Among patient-spousal caregivers, higher levels of dyadic distress were associated with higher levels of unmet needs, relationship dissatisfaction or low quality, being female, use of negative coping strategies and higher caregiving burden (Baucom et al., 2012; Lafaye et al., 2014; Milbury et al., 2013; Northouse et al., 2012; Rottmann et al., 2015; Segrin & Badger, 2014). These findings support the interconnected nature of distress, relationship quality, coping and caregiver burden among adult oncology patients and their spousal caregivers.

In contrast, studies about caregivers of AYA oncology patients are limited to parental caregivers of AYAs aged 11 to 24, with only one known study to date examining the shared experience of stress between AYA patients (ages 12 to 24) and their parental caregivers (Juth et al., 2015). Parental caregivers reported distress, isolation, and decrements in their own physical and emotional health, as well as challenges managing their households and other children (Barling et al., 2013; Grinyer, 2006). Non-parental caregivers (e.g., spouses, partners, friends) of AYAs are often included in studies with a large age range study sample (e.g., 16-85; Lambert et al., 2012), which limits the generalizability of the findings to the AYA population.

Recommendations

As AYAs continue to report complex unmet health and supportive care needs, including the need for mental health and family therapy (Kent et al., 2013; Smith et al., 2013; Yanez et al., 2013; Zebrack et al., 2013, 2014), researchers and healthcare providers need to expand their perspective from just focusing on the individual patient and consider how distress is shared among patients and those closest to them, such as their caregiver. Three research and clinical recommendations are provided to support the development of a relational and systemic

perspective, particularly as it relates to understanding the dyadic nature of coping and distress among AYA oncology patients and their caregivers.

Identifying the caregivers of AYA oncology patients. Before aiming to understand the shared experience of cancer among AYA patients and their caregivers, it is necessary to identify the caregivers. In the AYA oncology literature, research about the caregivers of patients has been mostly limited to parental caregivers of patients aged 11 to 24 years (Barling, Stevens, & Davis, 2013; Grinyer, 2006, 2008, 2009; Juth et al., 2015; Lewis, Mooney-Somers, Jordens, & Kerridge, 2014). While LIVESTRONG reported that 82% of AYAs identified a parent as a primary caregiver (Nass & Patlak, 2013), the methodology that led to these findings is unknown and thus cannot be generalized to the general AYA oncology population. It is plausible that their sample was heavily skewed by AYAs of a younger age (ages 11 to 24), who are recognized for relying on parents for caregiving (Decker, 2007; Grinyer, 2006).

There remains a dearth of literature about how AYAs identify their caregivers and how this changes across the age range and in relation to other sociodemographic variables, such as race, gender, sexual orientation, nation of origin, and marital status. The individual that constitutes a caregiver may differ or change by age at diagnosis within the AYA patient population. In addition, as the AYA survives and ages chronologically the caregiver may transition from parents to individuals outside the family structure, such as intimate partners or friends. Further research about the caregivers of AYAs will assist healthcare providers to revise assumptions that parents are the primary caregivers across the entire age range and that the needs of caregivers are the same across it.

Recognizing cancer as a shared experience between AYA patients and their caregivers. In the general adult oncology literature, cancer is well-recognized as being a shared

experience between patients and their caregivers (Badr et al., 2011; Davis-Ali, Chesler, & Chesney, 1993; Manne et al., 2010; Traa et al., 2015); however, research specific to AYA oncology patients continues to target patients (Dyson et al., 2012; Keegan et al., 2012; Kent et al., 2013; Smith et al., 2013; Zebrack et al., 2013, 2014). Support from family and friends is recognized as important to AYA patients' adjustment (Bellizzi et al., 2012; Carpentier & Fortenberry, 2010; Decker, 2007; Enskär & von Essen, 2007; Goodall et al., 2012; Miedema et al., 2007; Zebrack, 2011; Zebrack et al., 2006), yet only one known study considered the shared experience of cancer among AYA patients and their caregivers (Juth et al., 2015) using dyadic research methods.

As AYA-specific cancer centers and programs continue to develop (Reed et al., 2014), it is important to consider whether a family-centered approach to care, which is more commonly utilized in pediatric settings (Holm, Patterson, & Gurney, 2003), is a better fit for addressing AYAs' inter- and intrapersonal needs. Family and friends are important to AYA patients' adjustment and ability to cope with cancer (Kwak et al., 2013; Kyngas et al., 2001; Woodgate, 2006). However, if these family and friends are themselves distressed and struggling with coping, their ability to help the patient may be limited. A family-centered model of care would be able to simultaneously attend to the patient and his or her caregiver or support system. As well, as programs continue to develop, it is important to incorporate evaluation measures to assess how AYA patients' are being met locally, rather than generalizing findings from studies based on national samples (Dyson et al., 2012; Keegan et al., 2012; Kent et al., 2013; Smith et al., 2013; Zebrack et al., 2013, 2014). Assessing patients' and caregivers' distress and overall quality of life should be incorporated into these evaluations.

Examining dyadic stress and coping among AYA oncology patients and their caregivers. With the recognition that cancer is a shared experience between AYA patients and their caregivers, additional research is needed to understand how patients and their caregivers manage stress and provide support to each other, within the context of their relationship. This recommendation aims to specifically increase understanding about the dyadic nature of distress and coping among this population, as supported by the STM of distress and coping (Bodenmann, 1995, 2005). STM posits that in the face of shared stressor, such as cancer, distress and coping are interrelated within the context of intimate relationships, such as the patient-caregiver dyad. Juth and colleagues (2015) are the first AYA researchers to examine the shared experience of stress among AYA patients and their parental caregivers. They found that AYA patients reported similar levels of stress as their parental caregivers and that stress was strongly influenced by the dyad's perceived severity of the illness.

The researchers, however, did not examine any other factors that could effect the dyad's stress, such as coping strategies, relationship quality, available support or caregiving burden, all of which are associated with dyadic distress in the general adult oncology literature (Baider et al., 2008; Baucom et al., 2012; Milbury et al., 2013; Segrin & Badger, 2014). Findings from the general adult oncology literature provide support for the interconnectedness of distress and coping among cancer patients and their caregivers, but more research is needed to understand how this looks similar or different among AYA oncology patients and their caregivers.

Conclusion

Increasing knowledge about the shared experience of cancer among AYA oncology patients and their caregivers aligns with several of the recommendations posed by the AYA O PRG Group (2006) including: (a) identifying the unique cancer burden among AYA patients, (b)

improving care to AYAs across the cancer continuum, and (c) promoting support of AYA cancer patients. In order to provide high quality care to AYAs, it is important to acknowledge that cancer is a shared experience among patients and their caregivers (Davis-Ali et al., 1993; Juth et al., 2015) and that failing to incorporate the caregiver in treatment may negatively impact the patient. By incorporating the caregivers of AYAs, researchers and healthcare providers may gain valuable insight about the unique experience of cancer among AYAs. Understanding the shared experiences of cancer among AYAs and their caregivers will also help program developers implement targeted multi-level services across the cancer continuum, while also providing support for AYA patients and their caregivers. Embracing a relational approach to AYAs with cancer by including their caregivers will support the field's goals of improving survival rates and addressing unmet needs (AYAO PRG, 2006).

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CHAPTER FOUR: METHODOLOGY: DISTRESS AND COPING AMONG AYA ONCOLOGY PATIENTS AND THEIR CAREGIVERS

Between 6% and 56% of AYA patients experience clinically significant levels of distress (Dyson et al., 2012; Hedström, Ljungman, & von Essen, 2005; Kwak et al., 2013; Yanez, Garcia, Victorson, & Salsman, 2013; Zabora, Brintzenhofesoc, Curbow, Hooker, & Piantadosi, 2001), that varies by age at diagnosis, cancer type, and psychosocial needs. Across multiple studies AYA cancer patients and survivors have reported that relationships with family and friends are important sources of support throughout the cancer experience (e.g., Bellizzi et al., 2012; Carpentier & Fortenberry, 2010; Decker, 2007; Enskär, Carlsson, Golsäter, & Hamrin, 1997; Goodall, King, Ewing, Smith, & Kenny, 2012; Miedema, Hamilton, & Easley, 2007; Zebrack, 2011; Zebrack, Bleyer, Albritton, Medearis, & Tang, 2006). However, family and friends can also be a source of distress for AYA patients, particularly those who are emotionally unavailable or unable to handle stress (Hilton, Emslie, Hunt, Chapple, & Ziebland, 2009; Miedema et al., 2007; Synder & Pearse, 2010; Zebrack, Chesler, & Kaplan, 2010).

Family and friends who may be serving in a caregiver role may also be struggling with their own distress (Barling, Stevens, & Davis, 2013; Grinyer, 2008). Research about the experiences of caregivers of AYAs with cancer is sparse and is limited to parental caregivers of younger AYAs, particularly those between the ages of 11 and 24 (Barling et al., 2013; Grinyer, 2002, 2006, 2008, 2009; Juth, Silver, & Sender, 2015; Lewis, Mooney-Somers, Jordens, & Kerridge, 2014). Parental caregivers of younger AYAs experience distress, isolation, and decrements in their own physical and emotional health (Barling et al., 2013; Grinyer, 2006; Juth et al., 2015). Distress among caregivers of adult cancer patients varies across time (Murray et al., 2010; Northouse, Katapodi, Schafenacker, & Weiss, 2012) and is associated with caregiver

burden (Bigatti, Wagner, Lydon-Lam, Steiner, & Miller, 2011; Fujinami et al., 2014; Milbury, Badr, Fossella, Pisters, & Carmack, 2013), and patients' distress (Hodges, Humphris, & Macfarlane, 2005; Northouse et al., 2012; Zwahlen, Hagenbuch, Carley, Recklitis, & Buchi, 2008), but these factors have not been specifically examined among caregivers of AYA oncology patients.

Project Purpose and Aims

AYAs face the potential of a dual crisis in having to deal with the complex developmental tasks of emerging adulthood (Arnett, 2000, 2003), as well as cancer-related stressors (Thomas, Seymour, Brien, Sawyer, & Ashley, 2006; Zebrack, 2011). AYAs do not face these stressors alone, but rather with the support of their friends and family, including their caregiver. A caregiver is defined as an individual who provides the patient with significant financial, practical and/or daily living support (Minaya et al., 2012; Waldron, Janke, Bechtel, Ramirez, & Cohen, 2013). Yet very little is known about how distress is experienced by the AYA cancer patient-caregiver dyad. There is some evidence to suggest that AYA patients and their caregivers experience similar levels of stress (Juth et al., 2015); however, the relationship between distress and coping among AYA cancer patients and their caregivers is an emerging area of research in the field of medical and family therapy research. This study aimed to provide insight regarding how relational dynamics among AYA patients and their caregivers influence their experience of distress as guided by the systemic transactional model (STM) of stress and coping (Bodenmann, 1995, 2005). STM posits that when a dyad (i.e., a patient and her or his caregiver) is faced with a shared stressor (i.e., cancer), partners within the dyad will cope with it individually and collectively as a unit which varies across time as the patient passes through the continuum of cancer care (Bodenmann, 1995, 2005).

Study Design

This cross sectional survey study was conducted to examine the relationship between patients' and caregivers' distress levels while taking into account: (a) patient and caregiver demographic variables, (b) patient and caregiver relationship satisfaction, (c) patient and caregiver coping strategies, and (d) caregiver burden among a national sample of AYAs with cancer and their caregivers. Self-administered surveys were available online through Qualtrics (Qualtrics, 2005) for eligible patients and caregivers to complete. The outcome of this study was self-reported distress. Distress takes a variety of forms, thus, three validated instruments of personal distress were included to measure the primary outcome: (a) the Distress Thermometer (DT; Roth et al., 1998), (b) the Patient Problem List (PPL; Roth et al., 1998), and (c) the Perceived Stress Scale (PSS; Cohen, Kamarck, & Mermelstein, 1983). The DT and PPL capture distress and problems experienced in the previous seven days and was specifically designed for use with cancer patients (Roth et al., 1998). The PSS provides an overall measure of perceived stress over the previous month (Cohen et al., 1983).

The predictor variables included in this study were relationship satisfaction as measured by the Relationship Assessment Scale (Hendrick, 1988), coping strategies as measured by the Coping Strategies Inventory – Short Form (Tobin, Holroyd, Reynolds, & Wigal, 1989) and caregiver burden as measured by the Zarit Burden Inventory (Zarit, Reever, & Bach-Peterson, 1980). All of the surveys, including the demographic survey are included in Appendix B and are discussed below.

The research questions guiding this study included:

RQ1: Who are the caregivers of young adults with cancer? How does the type of caregiver (e.g., parent, spouse, sibling, friend) vary across sociodemographic variables?

RQ2: What is the association between distress, coping strategies, and relationship satisfaction among a sample of AYAs with cancer?

RQ3: What is the association between distress, coping strategies, relationship satisfaction and caregiver burden among a sample of caregivers of young adults with cancer?

RQ4: What is the association between dyadic distress and coping strategies among a sample of matched AYA oncology patients and their caregivers?

Hypotheses

1. Who the caregiver is (e.g., parent, spouse, sibling, friend) will vary across sociodemographic variables. Patients with parental caregivers will be younger than those patients who have non-parental caregivers (Juth et al., 2015; Woodgate, 2006).
2. Patients who report lower relationship satisfaction, higher use of problem-focused coping strategies, and lower use of emotion-focused coping strategies will report higher distress.
3. Caregivers who report lower relationship satisfaction, higher use of problem-focused coping strategies, lower use of emotion-focused coping strategies, and higher burden will report higher distress.
4. Coping and distress will be interconnected among patients and caregivers. Patients' use of coping strategies will be associated with their and their caregivers' distress. Caregivers' use of coping strategies will be associated with their and the patient's distress.

During the execution of this study based on the methods included here, two additional research questions were identified. The study was initially proposed as a dyadic research design to include patients and their caregivers; however, because patients and caregivers were eligible to participate irrespective if the other member of their dyad participated, this resulted in three

samples of participants. A sample of unmatched patients, unmatched caregivers, and matched patient-caregiver dyads. Having these three samples allowed for an examination of differences between patients in the unmatched and matched samples, as well as differences between caregivers in the unmatched and matched samples. Addition of these additional questions did not change the way that participants were recruited or how the research protocol was used. The two additional research questions added were:

1. Are patients who participated in the dyadic portion different from those patients who did not participate in the dyadic portion?
2. Are caregivers who participated in the dyadic portion different from those caregivers who did not participate in the dyadic portion?

Approval was obtained from the East Carolina University Institutional Review Board prior to data collection.

Participants

For this study, AYA cancer patients and their caregivers were invited to participate in an online survey about coping strategies, distress, caregiver burden, and the dyad relationship. Participants self-identified themselves as a patient or caregiver, which was confirmed by their responses to the screening criteria. As defined by National Cancer Institute Adolescent and Young Adult Oncology Progress Review Group (AYAO PRG), an AYA oncology patient is an individual who is diagnosed with cancer between the ages of 15 and 39 (AYAO PRG, 2006). In this study, only individuals over the age of 18 participated due to the challenges of receiving assent from minors and consent from their parents through an anonymous online survey.

For the purpose of this study, a caregiver may be a family member, a spouse or partner, a friend, or any other caregiver who has provided support to an AYA while the AYA had cancer

(Carey, Clinton-Mcharg, Sanson-Fisher, & Shakeshaft, 2012; Waldron et al., 2013; Weitzner, Jacobsen, Wagner, & Friedland, 1999). A primary caregiver is one who assumes a major responsibility for the care of the patient (Deatruck et al., 2014). Healthcare team members did not qualify as a caregiver. Only one caregiver was recruited per patient for a 1:1 dyad.

Patients were eligible if they meet the following inclusion criteria: (a) were between the ages of 18 and 41 at the time the online survey was completed, (b) were diagnosed for the first time with any cancer during the 24 months prior to the date of completing the study surveys, (b) were between the age of 16 and 39 at time of diagnosis, (c) were receiving or had completed cancer treatment within the previous 12 months of taking the study surveys, (d) were literate in written English, (e) were able to comprehend and electronically sign the consent form and (f) resided in the United States. The exclusionary criterion was a previous history of cancer. All cancers were included due to using online recruitment strategies, which would maximize opportunities to enroll dyads, since incidence of cancer types vary within the target age group. Participation was limited to those diagnosed within the previous two years in order to capture the experience of distress among AYA patients and their caregivers through treatment and in the early phases of survivorship. This time is marked by high levels of distress among AYA patients (Enskär & von Essen, 2007; Trevino et al., 2012; Yanez et al., 2013) and caregivers (Lambert, Jones, Girgis, & Lecathelinais, 2012; Milbury et al., 2013). As well, this is the time during which the healthcare system has the most opportunity to intervene because patients and their caregivers are still actively engaged with the system.

Caregivers were eligible for the study if he or she: (a) were at least 18 years old at the time of completing the survey, (b) endorsed that he or she served as a primary support person for an AYA patient during the patient's treatment within the previous two years, (c) was literate in

written English, (d) was able to comprehend and electronically sign the consent form, and (e) resided in the United States. The only exclusionary criterion was a personal history of cancer.

Recruitment

Multiple recruitment methods were employed to maximize enrollment. Patients and caregivers were recruited primarily through online social networking (e.g., Facebook and Twitter). Online recruitment is reported as being a cost-effective and time-efficient means of recruitment and data collection with AYA oncology patients (Gorman et al., 2014; Rabin, Horowitz, & Marcus, 2013). Furthermore, the first author also contacted colleagues in her professional and personal network and asked them to disseminate information about the study through their networks, including posting to their social media sites, emailing it to their network, and by sharing information about the study with patients or caregivers at their place of employment. The first author also posted flyers in public places (e.g., coffee shops, libraries, community centers) that did not require additional approvals.

The first author and a master's graduate student who served as a research assistant targeted Facebook pages and Twitter accounts that provide support or information to cancer patients or caregivers. Appendix D includes a list of all of the 401 Facebook pages and 102 Twitter accounts that the first author and research assistant posted announcements to between July 2015 and February 2016. Depending on the Facebook page's settings, the study announcement was either posted to the main page or to a visitor wall. As well, some page owners reposted the study announcement on behalf of the first author or research assistant. Reposting by the page owner was more common among owners who personally knew the first author or the research assistant. The goal was to post an invitation to participate in the research study to at least five Facebook or Twitter pages daily which equates to approximately 1,370 posts. Some

days it was not possible to post an invitation. There was no consistent pattern regarding which day of the week or what time of the day, the author or assistant posted announcements.

As well, flyers with information about this study were sent to individuals within the first author's professional and personal network for dissemination among other non-profit organizations that work with AYA cancer patients and/or their caregivers (see flyer in Appendix A). The flyer provided information about the study and contact information for the study's team.

Patients and caregivers of AYA oncology patients were recruited simultaneously through the methods discussed above. Patients and caregivers also served as sources of recruitment. When a patient opened the Qualtrics survey, she or he was asked to share information about enrollment and participation with their caregiver by sharing a link to the study with her or his caregiver or by entering the caregivers' email address into Qualtrics to which Qualtrics sent an invitation email. The same link and option to enter the caregiver's email address was provided at the end of the study to encourage the patient to contact her or his caregiver and share information about the study with that individual. If the patient chose to enter her or his caregiver's email address into Qualtrics, Qualtrics sent the caregiver an email asking them to participate in the study. The same feature was utilized in the caregiver's version of the online survey. While the goal of this study was to collect dyadic data from patients and their caregivers, patients and caregivers were able to participate in the study irrespective if their caregiver or patient participated in the study. This approach for recruiting patients and their caregivers was innovative because the goal was to recruit participants from across the United States in which to measure the shared experience of distress among a dyad. The limitation of allowing participants to self-select themselves was that the survey may not be completed by both partners of the dyad

and participation bias and information bias cannot be eliminated. Methods for linking data between patients and caregivers are discussed in the data collection section below.

Study Variables and Instruments

This study aimed to answer six research questions:

1. Who are the caregivers of young adults with cancer? How does the type of caregiver (e.g., parent, spouse, sibling, friend) vary across sociodemographic variables?
2. What is the association between distress, coping strategies, and relationship satisfaction among a sample of AYAs with cancer?
3. What is the association between distress, coping strategies, relationship satisfaction and caregiver burden among a sample of caregivers of young adults with cancer?
4. What is the association between dyadic distress and coping strategies among a sample of matched AYA oncology patients and their caregivers?
5. Are patients who participated in the dyadic portion different from those patients who did not participate in the dyadic portion?
6. Are caregivers who participated in the dyadic portion different from those caregivers who did not participate in the dyadic portion?

Predictor Variables

Independent variables for participants included basic demographic information (e.g., age, cancer type, ethnicity, education, income, insurance status; see Appendix B), relationship satisfaction, and coping strategies. Caregiver burden was also included as a predictor variable for caregivers. All of the measures included have successfully been used with AYA oncology patients, young adults, caregivers of patients with health issues, or caregivers of cancer patients.

All of the measures included here were self-reported in the online survey by participants. All of the measures are featured in Appendix B.

Relationship Assessment Scale. The Relationship Assessment Scale (RAS; Hendrick, 1988; Hendrick, Dicke, & Hendrick, 1998) is a 7-item, Likert Scale (1-5) that measures general relationship satisfaction between the patient and his or her primary caregiver. The RAS has been successfully used with non-romantic samples through a slight change in the wording (e.g., replacing partner with friend; Renshaw, McKnight, Caska, & Blais, 2010; Rodriguez, Ratanasiripong, Hayashino, & Locks, 2014). For the purposes of this study, “partner” in the original version was replaced with “caregiver” or “individual you are caring for,” for patients and caregivers, respectfully. An example of a patient question is, “How well does your caregiver meet your needs?” Participants answered each question using a 5-point scale ranging from 1 (low satisfaction) to 5 (high satisfaction). Items 4 and 7 are reverse scored and then all 7 responses are summed together for a total score. The total score was used in the data analysis. A higher score indicates a higher level of relationship satisfaction.

The RAS has shown good reliability and validity for romantic (Hendrick et al., 1998) and non-romantic relationships (Renshaw et al., 2010). Hendrick and colleagues (1998) reported good internal consistency (Cronbach’s alpha = .86), high test-retest reliability ($r = .85$) and high correlation with the Dyadic Adjustment Scale ($r = .87$) and the Kansas Marital Satisfaction Scale ($r = .64$ for men and $r = .74$ for women). Among a sample of more than 1000 undergraduate students, Renshaw and colleagues (2010) reported good internal consistency and test-retest reliability across a variety of close relationships. The Cronbach’s alpha coefficients were .89 for parents, .87 for friends, .90 for romantic partners and .86 for other relatives (Renshaw et al., 2010). The test-retest reliability scores for the RAS were .87 for parents, .74 for romantic

partners, .78 for friends, and .89 for other relatives (Renshaw et al., 2010). The RAS has been successfully used with bi-cultural and Spanish speaking samples (Contreras, Hendrick, & Hendrick, 1996; Hendrick et al., 1998), cancer patients (Garos, Kluck, & Aronoff, 2007; Segrin, Badger, Dorros, Meek, & Lopez, 2007; Shapiro et al., 2001) and cancer caregivers (Garos et al., 2007; Segrin et al., 2007). Permission to use the RAS was received via email from Dr. Susan Hendrick and a copy of this permission is featured in Appendix C.

Coping Strategies. The Coping Strategies Inventory – Short Form (CSI-S; Tobin et al., 1989) is a 32-item, Likert scale (0 – 4) that measures an individual’s coping strategies. The CSI-S is an abbreviated version of the original 72-item scale (Tobin et al., 1989). Participants were instructed to determine to what extent they have used the coping strategy featured in the question. An example statement is, “I talked to someone about how I was feeling.” Participants were instructed to mark, “not at all, a little, somewhat, much, and very much.” Not at all was scored as a 0 and very much was scored as a 4. Scores were summed for the eight primary subscales, which were then summed into four secondary subscales and then into two tertiary subscales. Scores from the two tertiary subscales were used in the data analysis. There are no cut-off scores; however, higher scores indicate greater use of the particular coping strategy.

Scoring for the CSI-S includes eight primary subscales, four secondary subscales, and two tertiary subscales (Tobin et al., 1989). The primary subscales are: (a) problem solving, (b) cognitive restructuring, (c) express emotion, (d) social contact, (e) problem avoidance, (f) wishful thinking, (g) self-criticism, and (h) social withdrawal (Tobin et al., 1989). The secondary subscales are: (a) problem focused engagement, which is a combination of problem solving and cognitive restructuring, (b) emotion focused engagement, which is a combination of social contact and expresses emotions, (c) problem focused disengagement, which is a combination of

problem avoidance, and wishful thinking and (d) emotion focused disengagement, which is a combination of social withdrawal and self-criticism (Tobin et al., 1989). The tertiary subscales are engagement (CSI-EC), which is a combination of problem and emotion focused engagement, and disengagement (CSI-DC), which is a combination of problem and emotion focused disengagement.

Tobin and colleagues (1989) provided evidence for the hierarchical factor structure and for the reliability and validity of the CSI with a sample of college students. Cronbach's alpha coefficients ranged from .72 to .94 for the primary subscales, .81 to .90 for the secondary subscales, and .89 to .90 for the tertiary subscales (Tobin et al., 1989). Test-retest correlations ranged from .67 to .83 for the primary subscales, .69 to .82 for the secondary subscales, and .78 to .79 for the tertiary subscales (Tobin et al., 1989). Additional psychometric evaluation of a 16-item version of the CSI has shown good reliability among a sample of African-American men and women (Addison et al., 2007). Cronbach's alpha coefficients varied from .58 to .72 for the secondary subscales and .59 to .70 for the tertiary subscales (Addison et al., 2007). The CSI has been shown to have good validity at differentiating depressed from non-depressed samples (Tobin et al., 1989) and neurotic from normal samples (Tobin et al., 1989). The CSI has been used with a sample of cancer patients (Chen et al., 1996; Compas et al., 1999; Hardy, Armstrong, Routh, Albrecht, & Davis, 1994), caregivers (García-Alberca et al., 2012; Hardy et al., 1994), and Spanish speaking participants (Hardy et al., 1994; Lobera et al., 2010) but reliability and validity was not assessed. As well, the measure has not been used nor reliability and validity assessed with AYA oncology patients. Permission to use the CSI was received via email from Dr. David Tobin and a copy of this email is featured in Appendix C.

The Zarit Burden Interview. The Zarit Burden Interview (ZBI; Zarit et al., 1980) is a 22-item, Likert scale (0 – 4) that measures caregivers' burden. The ZBI was initially published in a 29-item format (Zarit et al., 1980) and shorter versions are also available but the 22-item version is most commonly used (Bachner & O'Rourke, 2007). A sample question is, "Do you feel angry when you are around your relative?" with the options to respond, "never, rarely, sometimes, quite frequently, or nearly always". At the top of the survey relative was defined to include the individual that the caregiver is providing care to. Never was scored as a 0 and nearly always was scored as a 4. Scores range from 0 to 88. A sum of all the items provided a global score to indicate overall burden (Zarit et al., 1980), which was used for data analysis. A score between 0 and 20 indicates little or no burden, a score between 21 and 40 indicates mild to moderate burden, a score between 41 and 60 indicates moderate to severe burden and a score between 61 and 88 indicates high burden (Hébert, Bravo, & Prévaille, 2000; Whitlatch, Zarit, & von Eye, 1991).

Multiple researchers have reported the ZBI to have good reliability and validity with a variety of populations (i.e., Bachner & O'Rourke, 2007; Bedard et al., 2001; Galindo-vazquez et al., 2014; Siegert, Jackson, Tennant, & Turner-Stokes, 2010; Zarit et al., 1980; Zarit, Orr, Zarit, 1985). The ZBI shows good internal consistency (Cronbach's alpha = 0.83 and 0.89) and test-retest reliability ($r = 0.71$) among a sample of caregivers of dementia patients (Zarit et al., 1985). Herbert and colleagues (2007) reported a Cronbach's alpha of .92 among a sample of caregivers in Canada. Good construct validity has also been reported among a sample of caregivers of patients with dementia (Zarit et al., 1980, Zarit et al., 1985) with at least acceptable correlations between the global score and activities of daily living ($r = .32$), social life restrictions ($r = .32$),

the Brief Symptom Inventory ($r = .41$), and the quality of relationship between the patient and caregiver ($r = -.57$; Zarit et al., 1985).

While some studies have found that scores on the ZBI are related to disease characteristics and sociodemographic factors (Uttl, Santacruz, Litvan, & Grafman, 1998), others did not report a similar correlation (Herbert et al., 2000; Zarit et al., 1980). The ZBI is available for free for non-funded academic research through a user agreement with Mapi Research Trust, which was completed on March 13, 2015 and is included in Appendix C. Only caregivers completed the ZBI.

Outcome Variables

The primary dependent variable for this study was patients and caregivers' distress levels. The primary measure of distress was the Distress Thermometer (Roth et al., 1998). The Patient Problem List (Roth et al., 1998) was utilized with the Distress Thermometer as that is how it was developed to be used (Dabrowski et al., 2007; Jacobsen & Ransom, 2007). As well, the Perceived Stress Scale (Cohen et al., 1983) was included because it provides an overall perspective about perceived stress.

Distress Thermometer. The Distress Thermometer (DT; Roth et al., 1998) was used as the primary measure of emotional distress. The DT has been implemented as a part of distress screening at most National Comprehensive Cancer Network (NCCN)-member institutions (Jacobsen & Ransom, 2007). The DT is a single-item self-report measure that is on an 11-point scale with 0 labeled as "No Distress", 5 labeled as "Moderate Distress" and 10 as "Extreme Distress" (Roth et al., 1998). Participants selected the number that best described their level of distress in the past seven days. A cut off score of 4 shows optimal sensitivity and specificity for detecting distress (Jacobsen et al., 2005). The DT score was used in the analysis.

The DT has been validated against several other well-validated distress screeners including the Hospital Anxiety and Depression Scale and the Brief Symptom Inventory (Jacobsen et al., 2007), the Center for Epidemiological Studies-Depression Scale and the ECOG Performance Status Scale (Ransom, Jacobsen, & Booth-Jones, 2006) in samples of predominantly White non-Hispanic (>80%), college educated patients (Jacobsen & Ransom, 2007; Ransom et al., 2006). The use of the DT for family members shows acceptable validity (r from 0.65 to 0.69) against the Hospital Anxiety and Depression Scale in a sample of spouses and family members of cancer patients (Zwahlen et al., 2008). Reliability information for the use of the DT with family members has not been determined yet.

The National Comprehensive Cancer Network has repeatedly identified that DT is a valuable tool for distress management among cancer patients (e.g., Hoffman, Zevon, & Cecchini, 2004; Holland & Bultz, 2007; Jacobsen & Ransom, 2007) and has been applied in multiple research and clinical settings (e.g., Dabrowski et al., 2007; Mitchell, 2007) including with AYA oncology patients (Palmer, Patterson, & Thompson, 2014). With patients, the DT has acceptable reliability (.70) and validity (.70) against these measures (Ransom et al., 2006).

Patient Problem List. The Patient Problem List (PPL; Dabrowski et al., 2007; Jacobsen & Ransom, 2007) was used as another measure of distress. The PPL was developed to be used alongside the DT to assess which problems are causing the patient distress (Dabrowski et al., 2007; Jacobsen & Ransom, 2007). The PPL has included 39 problems divided into five categories: practical problems, family problems, emotional problems, spiritual/religious concerns, and physical problems (Dabrowski et al., 2007; Jacobsen & Ransom, 2007). Participants endorsed experiencing any of the problems “in the past week” by marking yes or no

(Dabrowski et al., 2007; Jacobsen & Ransom, 2007). The total number of problems endorsed was utilized in the analysis.

The PPL shows acceptable internal consistency with Cronbach alpha values ranging from 0.60 to 0.90 for the five categories and the total Problem List score (Tuinman, Gazendam-Donofrio, & Hoekstra-Weebers, 2008). The DT and PPL are available for personal use in research without special permissions (<http://www.nccn.org/about/permissions/thermometer.aspx>; Appendix C).

Perceived Stress Scale. The Perceived Stress Scale (PSS-10; Cohen et al., 1983) provides an overall measure of perceived stress (Cohen et al., 1983). While the DT measures an individual's emotional state in response to stress and the PPL measures an individual's current biopsychosocial problems (Roth et al., 1998), the PSS measures how situations in an individual's life are cognitively appraised as being stressful and asks participants to think about stress over the previous month (Cohen et al., 1983). In contrast, the DT and PPL ask about distress and problems in the previous week and captures the emotional response associated with stress (Roth et al., 1998). Taken together, these measures provide a more holistic picture of the distress that patients and caregivers are experiencing.

The PSS is a 10-item Likert scale (0 – 4) that measures how stressful an individual perceives their current situation or life to be (Cohen et al., 1983). The PSS was originally developed as a 14-item scale and a shorter 4-item scale is also available, however the 10-item shows the best reliability and validity across studies (Lee, 2012). A participant's score was obtained by reversing the response to six questions (questions 4, 5, 7, & 8, 10) and then summing all of the items. A participant's total score on the PSS was used for data analysis. Total scores on the PSS range from 0 to 40, with higher scores indicating higher levels of perceived stress. There

are no specific cut-offs for the classification of high or low stress. A sample question is, “In the last month, how often have you felt that you were unable to control the important things in your life?” with the options to respond, “never, almost never, sometimes, fairly often, and very often.”

The PSS has shown to have good reliability and satisfactory validity in a sample of college students and participants in a smoking cessation program (Cohen et al., 1983; Cohen & Williamson, 1988). Cronbach’s alpha coefficients for reliability ranged from 0.84 to 0.86 (Cohen et al., 1983). The measure also has good test-retest reliability when administered two days apart ($r = 0.85$; Cohen et al., 1983). Criterion validity was demonstrated by correlations with the number of life events ($r = 0.20$) and impact of life events ($r = 0.35$; Cohen et al., 1983).

Additional psychometrics studies of the PSS have been completed and demonstrate good reliability and validity among diverse samples of participants including college students, psychiatric patients, Japanese students, HIV-positive patients, survivors of a family members that committed suicide, teachers, medical students, pregnant and post-partum women, policewomen, technical workers and in the contexts of a smoking-cessation program, a health-promotion program, and a cardiac-rehabilitation program, (Lee, 2012). The Cronbach’s alpha coefficient was greater than 0.70 for the 12 studies in which it was used (Lee, 2012). Test-retest reliability was greater than 0.70 for the 4 studies in which it was assessed (Lee, 2012). The PSS was also shown to have at least a moderate correlation with the Center for Epidemiologic Studies Depression Scale, Inventory to Diagnose Depression, Beck Depression Inventory, Hospital Anxiety and Depression Scale, State-Trait Anxiety Inventory, Escala de Cansancio Emocional, General Health Questionnaire, Edinburgh Postnatal Depression Scale, Thai Depression Inventory and Depression Anxiety Stress Scale-21 (Lee, 2012). The PSS is available for personal use in

nonprofit research without special permissions (<http://www.psy.cmu.edu/~scohen/scales.html>; Appendix C).

The combined survey included a demographic questionnaire, the DT and PPL (Roth et al., 1998), the PSS (Cohen et al., 1983), the RAS (Hendrick, 1988) and the CSI (Tobin et al., 1989). Caregiver participants also completed the ZBI (Zarit et al., 1980). Patients were asked to complete 93 survey questions. Caregivers were asked to complete 105 survey questions. During the development of this methodology, three individuals completed the combined caregiver survey on paper in less than 30 minutes. Patient participants completed the online survey in 18 minutes on average. Caregiver participants completed the online survey in 20 minutes on average.

Data Collection and Procedures

A survey method was used to gather data to answer the study's research questions. Data collection was completed through Qualtrics (Qualtrics, 2005). Qualtrics is a secure website that ensures privacy and provides participants convenience for completing the study surveys. When participants opened Qualtrics, they first completed a brief screening questionnaire to ensure they met the inclusion and exclusion criteria (Appendix A). If the inclusion criteria were met, participants completed an electronic consent form (Appendix A). Following consent, the next screen discussed the dyadic nature of this study and included a link for the participant to share with the other half of her or his dyad. For example, if a patient was participating, the link included was for her or his caregiver.

Following consent, participants completed a demographic questionnaire. As a part of the demographic questionnaire, participants were asked to provide the first two letters of their and their primary caregiver's (or the patient's, if the participant was a caregiver) first and last name and current age. By entering this information, the participant was providing permission for the

research team to link her or his data with her or his caregiver/patient. This information was used to link patients and their caregivers during data analysis to create a dyad. Note: The Associate Administrative Director with the ECU IRB confirmed that this information can be gathered from patients and caregivers because this study does not fall under HIPAA regulations (see Appendix A).

After the participant completed the demographic questionnaire, the participant completed the following measures in the order presented: (a) the DT (Roth et al., 1998), (b) the PPL (Roth et al., 1998), (c) the PSS (Cohen et al., 1983), (c) the CSI (Tobin et al., 1989), and (d) the RAS (Hendrick, 1988). Caregivers completed each of the instruments above, in the same order, and also completed the ZBI (Zarit et al., 1980). Participants were instructed to complete the entire survey in one setting. The specific order of the surveys was chosen to account for potential survey fatigue and attrition. At the end of the survey, again, a screen appeared that included information about the dyadic nature of this study and encouraged the participant to share a study link with or enter the email address of the other half of her or his dyad.

This study used an incentive for participant recruitment. Patients and caregivers had the option of entering their contact information into a separate Qualtrics survey after they completed the study measures for a chance to win one of twenty \$10 Amazon gift cards for their participation in the study. Survey results were kept separate from the participants' contact information by storing the two sets of data in different Qualtrics surveys. Gift cards were mailed to 20 randomly selected participants.

Once data collection was complete, the data were exported into a csv file for data analysis in IBM SPSS 22.0 (IBM Corp., 2013) and RStudio (Rstudio, 2012). Data will be stored in Qualtrics at ECU for seven years, per the university's research data storage policies. Dr.

Hodgson was the primary investigator on the Qualtrics surveys and oversaw data collection and storage to ensure that all federal and institutional research policies were followed.

Statistical Analyses

Prior to modeling the data, descriptive univariate and bivariate analyses were completed. Descriptive univariate analyses were completed to summarize the data and provide demographic characteristics of the samples. Means and standard deviations of all continuous variables (e.g., age, DT scores, PSS scores, CSI scores, ZBI scores) were examined while counts for categorical data (e.g., gender, race, ethnicity, cancer type, marital status) were examined. Bivariate analyses included a mix of Pearson and Spearman correlations, contingency tables with chi-square tests, t-tests or ANOVA tests to examine relationships among and between variables. Pearson and Spearman correlations were completed for continuous variables, such as DT and CSI scores. Chi-square tests were completed for categorical variables, such as cancer types, race, and gender. ANOVAs and t-tests were completed for correlating continuous variables with categorical variables, such as DT scores and gender or comparing DT scores between patients and caregivers.

Descriptive univariate and bivariate analyses were used to address the first research hypothesis, frequencies and bar graphs were used to describe the frequency of different types of caregivers (i.e., parent, spouse, friend, relative, etc.). Additional bivariate chi-square tests were completed to compare the type of caregiver across categorical variables such as gender and type of cancer. ANOVAs and t-tests were completed for comparing continuous variables across type of caregiver. For example, an ANOVA with the Bonferroni post-hoc test was completed to examine the mean age of patients across the different types of caregivers (e.g., parent, friend, spouse, dating partner). Independent samples t-tests were also utilized to address the additional

two research questions that were added during the study, which aimed to examine the differences between matched and unmatched patients, and caregivers, respectively.

To address the second and third research questions regarding the association between distress, coping and relationship satisfaction among young adult patients and caregivers, respectively, multiple linear regressions were used. Three separate models were developed for patients. The first model included DT as the outcome variable and engagement coping (CSI-ECU), disengagement coping (CSI-DC), and RAS as predictor variables. The second model included the PPL as the outcome variables and CSI-EC, CSI-DC, and RAS as predictor variables. The third model included PSS as the outcome variable and CSI-EC, CSI-DC, and RAS as predictor variables. All of the models included treatment phase and participant age as control variables.

Similarly, three separate models were examined for caregivers. The first model included DT as the outcome variable and CSI-EC, CSI-DC, RAS and ZBI as predictor variables. The second model included PPL as the outcome variable and CSI-EC, CSI-DC, RAS and ZBI as predictor variables. The third model included PSS as the outcome variable and CSI-EC, CSI-DC, RAS and ZBI as predictor variables. All of the models included treatment phase and participant age as control variables.

To address the fourth research question, an actor-partner interdependence model (APIM) was evaluated using structural equation modeling (SEM; Kenny, Kashy & Cook, 2006). APIM is designed to measure and account for the interdependence of data collected from matched dyads (Kenny, Kashy & Cook, 2006), such as patients and their caregivers. When data are collected from two related individuals, their data cannot be treated as independent observations (Cook & Kenny, 2005). Commonly used statistical analyses such as multiple regressions or ANOVAs

assume that the predictor and outcome variables are independent among participants. If multiple regressions or ANOVAs were used to analyze non-independent data without accounting for the non-independence, it could lead to an inaccurate test statistic and degrees of freedom, which would then result in a biased p -value (Kenny, Kashy, & Bolger, 1998).

With dyadic data, APIM measures how predictor and outcome variables vary between and within dyads, while also accounting for intra- and interpersonal variation (Kenny, Kashy, & Cook, 2006). APIM can estimate three types of effects: actor, partner, and actor by partner interaction effects (Kenny, Kashy & Cook, 2006). The actor effect is the estimation of each person's predictor variables on his or her own outcome variable (Kenny, Kashy & Cook, 2006). The partner effect is the estimate of one person's predictor variables on the partner's outcome variable (Kenny, Kashy & Cook, 2006). The actor-partner interaction effect is similar to the interaction term in multiple regressions (Cook & Kenny, 2005).

Structural Equation Modeling (SEM) is an efficient and well-documented alternative to Ordinary Least Squares (OLS) for modeling an APIM because it allows for the simultaneous testing of actor, and partner, while controlling for the other effects (Kenny, Kashy, & Cook, 2006). There are three assumptions that must be met for completing APIM with SEM: (a) multivariate normality, (b) minimum sample size, and (c) model identification (Kenny, Kashy, & Cook, 2006). Model identification is necessary if the number of unknown parameters is greater than the number of known correlations or covariances (Kline, 2011). When the number of unknown parameters equals the number of known covariances, then the model is determined to be "just identified" (Kenny, Kashy, & Cook, 2006; Kline, 2011). Unstandardized variables should be used within the model as standardized data makes it challenging to compare effects across the dyad (Kenny, Kashy, & Cook, 2006).

SEM allows for inclusion of predictor variables as well as covariates, such as demographic information. Coefficients for actor and partner effects are interpreted similar to how they are interpreted in multiple regressions. As well, using APIM allows for residual errors from the variables to be correlated, which accounts for additional interdependence that is not captured in the actor or partner effects (Cook & Kenny, 2005).

APIM using SEM was completed using the lavaan package (Yves, 2012) in Rstudio (Rstudio, 2012). Nine separate APIM models were assessed to answer the question about how distress and coping are interrelated among patients and their caregivers. In three of the models, DT scores were the outcome variable. In three of the models, PPL was the outcome variable. In three of the models, PSS were the outcome variable. In three of the models, the predictor variable was CSI-EC. In three of the models, the predictor variable was CSI-DC. In three of the models, RAS scores were the predictor variables. In a basic APIM which has one set of predictors and one set of outcomes, model of fit does not need to be assessed because it is a “just identified” model (Kenny, Kashy, & Cook, 2006; Kline, 2011). Path coefficients provide estimates of the actor and partner effects.

Sample Size Estimates

There is significant variation in the literature regarding the minimal required sample size to detect differences when using APIM. In APIM, the unit of analysis is the dyad, rather than the individuals within the dyad (Cook & Kenny, 2005; Kenny & Cook, 1999; Kenny, Kashy, & Cook, 2006). Kenney and Cook (1999) reported that the sample size requirements for the number of dyads for APIM using SEM are the same as the sample size required for multiple linear regression. Based on this recommendation, the minimum number of dyads with seven proposed predictors (i.e., coping strategies, relationship satisfaction, caregiver burden, type of caregiver,

gender, race and SES) that is necessary to detect: (a) small effects is 755 dyads, (b) medium effects is 108 dyads, and (c) large effects is 52 dyads (Faul, Erdfelder, Buchner, & Lang, 2009).

In contrast, Olsen and Kenny (2006) recommended that the minimum number of dyads plus one equal twice the number of variables in the APIM model in order to detect medium to large effects. Based on this recommendation, an APIM model that includes seven proposed predictors (i.e., coping strategies, relationship satisfaction, caregiver burden, type of caregiver, gender, race and SES) and one outcome variable (i.e., distress) would require a minimum of 15 dyads.

Recently, Kenny and Ackerman (n.d.) developed an online calculator that estimates a minimum sample size for APIM based on desired power and effect sizes (<https://robert-ackerman.shinyapps.io/APIMPowerR/>). A paucity of existing data on the effect of relationship satisfaction and coping on patient and caregiver distress levels among young adult cancer patients means effect sizes are not readily obtained from the literature. Therefore, Cohen's (1992) guidelines for small ($d = 0.2$), medium ($d = 0.5$) and large effects ($d = 0.8$) were used to calculate sample sizes. Based on outcomes from this calculator, the minimum number of dyads needed to detect: (a) small effects is 387 dyads, (b) medium effects is 72 dyads, and (c) large effects is 48 dyads (Kenny & Ackerman, n.d.).

Previous researchers have examined distress among cancer patient-caregiver dyads with sample sizes as small as 15 dyads (Kaye & Gracely, 1993) and as large as 288 dyads (Baider & Denour, 1999). Researchers reported significant differences with APIM using SEM with 81-98 patient-caregiver dyads (Dorros, Card, Segrin, & Badger, 2010; Lim, Shon, Paek, & Daly, 2014; Manne et al., 2004). Based on the three methods of estimating sample sizes for dyadic data analysis with APIM discussed (Kenny & Ackerman, n.d.; Kenny & Cook, 1999; Olsen & Kenny,

2006) and the published sample sizes from previous studies, the study aimed to enroll one hundred dyads. Recruitment lasted approximately eight months. At the end of each month, recruitment strategies and enrollment numbers were assessed and adjustments to the recruitment strategy were made. Adjustments included identifying additional network contacts and considering additional Facebook pages and Twitter accounts to contact.

Summary

This purpose of this study was to examine the association between relationship dynamics, including patient-caregiver relationship satisfaction, coping strategies and caregiver burden, and distress levels among AYA cancer patients and their caregivers. Patients and caregivers participated in an online survey posted on Facebook and Twitter. Data were collected over an eight month period between late fall 2015 and early spring 2016. Analyses were conducted with multiple linear regression and actor-partner interdependence models (APIM) using structural equation modeling (SEM).

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CHAPTER FIVE: THE EXPERIENCE OF DISTRESS AND COPING AMONG YOUNG ADULTS WITH CANCER AND THEIR CAREGIVERS

Researchers reported that between 6% and 56% of adolescent and young adult cancer patients experience clinically significant levels of distress (Dyson, Thompson, Palmer, Thomas, & Schofield, 2012; Kwak et al., 2013; Zebrack et al., 2014). Adolescents and young adults (AYAs) with cancer may experience distress due to a variety of reasons including physical side-effects, altered body image, feelings of isolation, hopelessness, and anxiety, changes in family and friend dynamics (Abrams, Hazen, & Penson, 2007; Hilton, Emslie, Hunt, Chapple, & Ziebland, 2009; Jones, 2008; Soliman & Agresta, 2008). AYA cancer patients cope in diverse ways with their illnesses (Decker, Haase, & Bell, 2007; Miedema, Hamilton, & Easley, 2007), including the use of emotion and problem focused coping (Kyngäs et al., 2001; Miedema et al., 2007; Snöbohm & Heiwe, 2013), as well as negative expression and support-seeking coping strategies (Trevino et al., 2012). However, use of emotion and problem focused coping is associated with better adjustment among young adults with cancer (Kyngäs et al., 2001; Miedema et al., 2007; Snöbohm & Heiwe, 2013).

As AYA oncology patients face cancer, caregivers provide valuable practical, emotional, financial and medical support (Stenberg, Ruland, & Miaskowski, 2010; Woodgate, 2006). Having this support helps AYAs manage their distress levels (Coyne, Wollin, & Creedy, 2012; Evan & Zeltzer, 2006); yet, little is known about how caregivers experience the distress of being a caregiver to an AYA patient and what coping strategies they use. In the adult oncology literature, caregivers reported multiple decrements in physical and psychosocial health (Girgis et al., 2013; Northouse et al., 2012; Stenberg et al., 2010). Some of the physical symptoms included greater frequency of headaches, fatigue, sleep troubles, back, neck and shoulder problems,

digestion problems and stress-related illnesses (Girgis et al., 2013). Caregivers also reported higher rates of anxiety and depression as compared to non-caregivers (Lambert, Girgis, Lecathelinais, & Stacey, 2013; Mellon, Northouse, & Weiss, 2006). Caregiver distress may be related to the type of care provided, the patient's symptoms, physical health and distress levels, the type of relationship, and caregiving burden (Applebaum & Breitbart, 2013; Dumont et al., 2006; Fujinami et al., 2014; Hodges, Humphris, & Macfarlane, 2005; Li et al., 2013; Northouse et al., 2012; Sharpe, Butow, Smith, McConnell, & Clarke, 2005; Stenberg, Cvancarova, Ekstedt, Olsson, & Ruland, 2014). Researchers who investigated the adult patient and spousal caregiver as a unit noted that positive dyadic coping is associated with better dyadic adjustment (Badr, Carmack, Kashy, Cristofanilli, & Revenson, 2010; Badr & Carmack Taylor, 2008; Manne, Badr, Zaider, Nelson, & Kissane, 2010), improved quality of life, reductions in symptoms of anxiety and depression (Lafaye et al., 2014), and increased mood (Berg et al., 2008).

To date, no known studies have looked at dyadic distress and coping among AYA patients and their caregivers. One study (Juth, Silver, & Sender, 2015) reported the shared experience of stress among AYA patients and their caregivers; however, they focused only on parental caregivers of patients between the ages of 12 and 24, and only examined the relationship between disease severity and posttraumatic stress symptoms. Researchers found that AYA patients reported similar levels of posttraumatic stress symptoms as their parental caregivers. It is important to note that this study did not examine the experience of stress among non-parental caregivers (e.g., spouses, friends) and did not include patients across the entire AYA range of 15 to 39 years old. Understanding the experience of other types of caregivers is necessary for developing a variety of resources for the diversity of caregivers that may present with an AYA patient. Juth and colleagues' (2015) study provided a preliminary understanding of the dyadic

nature of stress among AYA patients and their caregivers and highlighted the need for studies about the interconnectedness of the experiences that patients and their caregivers are experiencing as they face cancer. Further research about the caregivers of AYAs will assist healthcare providers to revise assumptions that parents are the primary caregivers across the entire age range and that the needs of caregivers are the same across it. The systemic transactional model (Bodenmann, 1995, 2005) provides a framework for exploring the interconnected nature of stress and coping among patients and their caregivers.

Systemic Transactional Model

The systemic transactional model (STM) posits that distress and coping are interrelated among individuals in a close relationship when faced with a shared stressor (Bodenmann, 1995, 2005). It supports that dyads can experience stress in multiple ways, including: (a) stress that only impacts one partner, (b) stress that directly impacts one partner and indirectly the other, and (c) stress that impacts both partners (Bodenmann, 1995, 2005). Cancer is an example of a shared or dyadic stressor because it has the potential to directly and indirectly impact the patient and her or his caregiver. Several researchers found strained dyadic coping, lower relationship quality, and increased distress levels reported among heterosexual patient-spousal dyads facing cancer (e.g., Badr, Carmack, Kashy, Cristofanilli, & Revenson, 2010; Feldman & Broussard, 2006; Manne et al., 2004; Traa, de Vries, Bodenmann, & Den Oudsten, 2015) but none have considered this from an AYA population perspective. As such, the research questions below were examined to learn more about the shared experience of distress among AYA oncology patients and their caregivers.

Assessing the multiple ways that distress can be experienced within a dyad can be accomplished through the use of the actor-partner interdependence model (APIM; Cook &

Kenny, 2005). In the APIM, the dyad is treated as the unit of analysis and participants' scores on predictor variables are used to predict both their own (actor effects) and their partners' (partner effect) scores on the outcome variable, after taking into account the dyad's interdependence on the predictor variable (Cook & Kenny, 2005). In the present study, participants' use of engagement and disengagement coping strategies will be treated as predictor variables, and measures of distress and perceived stress will serve as the outcome variables. The following research questions will help expand what is known about AYA patients, caregivers, and their transactional relationship.

RQ1: Who are the caregivers of young adults with cancer? How does the type of caregiver (e.g., parent, spouse, sibling, friend) vary across sociodemographic variables?

RQ2: Are patients who participated in the dyadic portion different from those patients who did not participate in the dyadic portion?

RQ3: Are caregivers who participated in the dyadic portion different from those caregivers who did not participate in the dyadic portion?

RQ4: What is the association between distress, coping strategies, and relationship satisfaction among a sample of AYAs with cancer?

RQ5: What is the association between distress, coping strategies, relationship satisfaction and caregiver burden among a sample of caregivers of young adults with cancer?

RQ6: What is the association between dyadic distress and coping strategies among a sample of matched AYA oncology patients and their caregivers?

Method

A descriptive, cross-sectional study design was utilized in this study to collect data from patients and caregivers about distress, coping strategies, relationship satisfaction, and caregiver

burden, as well as several demographic variables. Data were collected through a self-administered online survey via Qualtrics (Qualtrics, 2005). While the goal of this study was to collect dyadic data from all patients and their caregivers, patients and caregivers were able to participate in the study irrespective of whether or not their caregiver or patient chose to participate. All study procedures were approved by a university Institutional Review Board.

Participants

This study aimed to gather a national sample of AYA patients and caregivers of AYA patients primarily through social media (e.g., Facebook, Twitter) and cancer networks. AYA participants were eligible at the time of accessing the Qualtrics survey if they were: (a) between the ages of 18 and 41, (b) diagnosed with any cancer for the first time within the past two years, and (c) receiving treatment or had completed treatment in the past year. Caregivers were eligible for the study at the time of accessing the Qualtrics survey if they were: (a) at least 18 years old, and (b) self-reported being a primary support person for an AYA patient during the patient's treatment for cancer within the previous two years and (c) had never had cancer themselves. All participants had to comprehend and sign the consent form and had to reside in the United States at the time of survey completion. A total of 113 patients and 56 caregivers met the study criteria and completed the study. Within the larger sample of patients and caregivers, there were 19 matched dyads.

Procedures

Announcements about the study were posted to 401 professional (e.g., Stupid Cancer, American Cancer Society) and personal (e.g., Cancer Caregiver Warriors, Hodgkin's Lymphoma Awareness) Facebook pages and 102 Twitter accounts (see Appendix D for full list) up to 12 times between July 2015 through February 2016. The announcement included a link to the

study's survey where potential participants first responded to eligibility questions, completed an electronic consent form, and completed the study survey. Prior to electronically submitting their completed survey, participants were asked to enter the email address of their dyad partner (e.g., if a patient was filling out the survey, they were asked to enter the email address of their caregiver), whom would receive an email inviting him or her to participate in the study. Participants had the option to be entered into a raffle for a \$10 gift card after completing the study.

Measures

All of the measures selected for this study demonstrate good reliability and validity for use among cancer patients, cancer caregivers, and/or young adults. Outcome measures included: (a) the Distress Thermometer (Roth et al., 1998), (b) the Patient Problem List (Roth et al., 1998), and the (c) Perceived Stress Scale (Cohen et al., 1983). The Distress Thermometer and the Patient Problem List served as indicators of acute distress, while scores from the Perceived Stress Scale provided an overall measure of stress. Predictor measures included: (a) the Coping Strategies Inventory (Tobin et al., 1989), (b) the Relationship Assessment Scale (Hendrick, 1988; Hendrick, Dicke, & Hendrick, 1998), and (c) caregivers also completed the Zarit Burden Inventory (Zarit et al., 1980).

Distress Thermometer. The Distress Thermometer (DT; (Roth et al., 1998) was used as the primary measure of emotional distress. The DT is a single-item self-report measure that is on an 11-point scale with 0 labeled as “No Distress,” 5 labeled as “Moderate Distress” and 10 as “Extreme Distress” (Roth et al., 1998). A higher DT score (range 0 – 10) indicated a higher level of distress.

Patient Problem List. The DT was used in conjunction with the Patient Problem List (Dabrowski et al., 2007; Jacobsen & Ransom, 2007). The Patient Problem List includes 39 problems across five categories: (1) practical problems, (2) family problems, (3) emotional problems, (4) spiritual/religious concerns, and (5) physical problems. Participants endorsed if they have experienced any of these biopsychosocial or practical problems in the past week by marking yes or no (Dabrowski et al., 2007; Jacobsen & Ransom, 2007). A greater number of problems (range 0-39) indicated higher levels of distress.

Perceived Stress Scale. The Perceived Stress Scale (PSS; Cohen et al., 1983) was included because it provides a more global perspective about stress as compared to the DT. The PSS is a 10-item, Likert scale (0 – 4) that measures how stressful an individual perceives their current situation or life to be (Cohen et al., 1983). Higher total scores (range 0 – 40) indicated higher levels of perceived stress.

Coping Strategies. The Coping Strategies Inventory – Short Form (CSI; Tobin et al., 1989) is a 32-item, Likert scale (0 – 4) that measured an individual’s coping strategies. The scores for the two tertiary subscales, engagement (CSI-EC) and disengagement (CSI-DC), were used in the data analysis. The CSI-EC include problem solving, cognitive restructuring, expressing emotions and social contract. The CSI-DC included problem avoidance, wishful thinking, self-criticism, and social withdrawal. The tertiary subscales were selected because they mostly align with terminology related to positive and negative coping that is utilized in the adult oncology literature (e.g., Badr et al., 2010; Feldman & Broussard, 2006; Lafaye et al., 2014; Manne et al., 2010; Rottmann et al., 2015). There are no cut-off scores; however, higher scores (range 0 – 64) indicate greater use of the particular coping strategy.

Relationship Assessment Scale. The Relationship Assessment Scale (RAS; Hendrick, 1988) is a 7-item, Likert Scale (1-5) that measured general relationship satisfaction between the patient and his or her primary caregiver. A higher score (range 5 – 35) indicated a higher level of relationship satisfaction.

The Zarit Burden Interview. The Zarit Burden Interview (ZBI; Zarit et al., 1980) is 22-item, Likert scale (0-4) that measured caregivers' burden. A higher score (range 0 – 88) indicated a higher level of burden.

Statistical Analyses

Descriptive univariate and bivariate analyses, using patient and caregiver data, were performed to examine and summarize how caregiver type varied across sociodemographic and clinical characteristics (RQ1). Chi-square and independent samples t-tests were used to compare characteristics between patients and caregivers who participated in the dyadic portion and those that did not (RQ2 and RQ3, respectively). The association between distress, coping and relationship satisfaction among young adult patients and caregivers, respectively, was assessed using multiple linear regressions (RQ4 and RQ5). Actor-partner interdependence models using structural equation modeling was used to examine the association between coping and distress among a sample of matched patients and their caregivers (RQ6). The analyses were completed using IBM SPSS 22.0 and RStudio (2012). The significance level was set to .05.

Results

Prior to conducting analyses to address the research questions, demographic variables of the study sample were examined. This study included three distinct samples: (a) an independent or sample of patients whose caregiver did not participate in the study (unmatched patients), (b) an independent sample of caregivers whose patient did not participate in the study (unmatched

caregivers), and (c) a sample of matched patients and their caregivers, where both members of the dyad participated in the study (dyadic sample). Table 1 detailed the demographic characteristics of patients and caregivers in the independent samples. The independent samples included 94 patients and 33 caregivers. Patients were on average 30.89 years of age ($SD = 5.65$, range 18-40) and caregivers were 38.12 years old ($SD = 13.38$, range 22-68). Patients in the sample reported that their caregivers were on average 43.72 years old ($SD = 12.58$, range 22-71). Caregivers in the sample reported they provided care to patients aged 27.79 ($SD = 6.09$, range 18-40). Table 2 details the demographic characteristics of patients and caregivers in the 19 dyadic sets. In the matched dyad sample, patients were on average 31.32 years old ($SD = 5.35$, range 22-39) and their caregivers were 40.68 years old ($SD = 11.82$, range 23-60).

Tables 3 and 4 provide clinical characteristics (e.g., type of cancer, type of treatment) about the samples. Both in the independent samples and in the dyadic sample, there were a mix of cancers represented including lymphoma, leukemia, sarcoma, breast, cervical, thyroid, melanoma, and colorectal. Patients also received a mix of treatments including surgery, chemotherapy, radiation, bone marrow transplants, and hormone replacement therapy.

Tables 5 details how study measures differed between patients and caregivers in the unmatched samples. In the unmatched samples, caregivers had higher DT ($t(56.2786) = 2.948$, $p < .01$) and PPL scores ($t(50.501) = 3.697$, $p < .01$) than patients. No other differences were identified between patients and caregivers. Table 6 details how study measures differed between patients and caregivers in the dyadic sample. There were no significant differences in any of the outcome or predictor measures between patients and their caregivers in the matched sample. Correlations were completed separately for patients and caregivers to assess each measures strength and direction and are also presented in Table 7 for the unmatched samples and Table 8

for the dyadic sample. The association between patients' and caregivers' outcome and predictor measures are provided in Table 9.

Research Question 1: Who are the caregivers of young adults with cancer? How does the type of caregiver (e.g., parent, spouse, sibling, friend) vary across sociodemographic variables?

Patients in the unmatched sample reported a mix of caregivers, including parents ($n = 30$), dating partners ($n = 17$), spouses ($n = 33$), family members ($n = 9$), and two patients reported not having a caregiver. There was a significant age difference among patients with different types of caregivers ($F(3,86) = 5.992, p = .001$). Post-hoc comparisons using the Bonferroni test indicated that patients who reported having a spouse as a caregiver were significantly older ($M = 32.03, SD = 4.51$) than patients who reported a parent ($M = 27.73, SD = 6.38$) and non-parent family member as a caregiver ($M = 25.22, SD = 3.34, p < .001$). Patients who reported being single or dating were more likely to report having a parent as a caregiver, while those who reported being married were more likely to report their spouse as their caregiver ($X^2(12) = 84.662, p < .001$). These two findings are likely confounded by the association between age and relationship status ($F(4,108) = 8.596, p < .001$). Patients who were either single ($M = 28.20, SD = 6.25$) or dating ($M = 28.15, SD = 5.94$) were significantly younger than patients who were married ($M = 33.50, SD = 3.84$) or divorced ($M = 33.67, SD = 2.52, p < .05$). These findings taken together suggest that younger AYAs are more likely to report parents are a caregiver while older AYAs are more likely to rely on a spouse if they are married.

Patients who reported a lower annual household income were more likely to report having a parent caregiver while patients who reported a higher income were more likely to report a spouse caregiver ($X^2(6) = 29.827, p < .01$). This may be heavily influenced that married

participants endorsed a household income that includes their spouse's income. The type of caregiver identified did not differ by patients' gender, race, sexual orientation, education level, employment status, number of dependents, or cancer type.

Data from caregivers also confirmed a mix of caregiver types and similar age effects. Caregivers reported being parents ($n = 12$), friends ($n = 1$), dating partners ($n = 8$), spouses ($n = 9$), and family members ($n = 3$). The age of the patient differed across the different caregiver types ($F(3,28) = 5.104, p < .01$). Post-hoc comparisons using the Bonferroni test indicated that caregivers who identified as being the patient's spouse were older ($M = 32.56, SD = 5.17$) than caregivers who identified as being the patient's parent ($M = 25.83, SD = 5.67$) or family members ($M = 21.33, SD = 2.52$). The type of caregiver did not differ by caregivers' gender, race, ethnicity, sexual orientation, education level, employment status, income, or by the AYA's type of cancer.

Research Question 2: Are patients who participated in the dyadic portion different from those patients who did not participate in the dyadic portion?

Independent samples t -tests were used to examine differences among patients in the unmatched sample as compared to those in the matched sample (Table 10). Patients in the dyadic sample a higher PPL ($M = 16.84, SD = 7.32$) as compared to unmatched patients ($M = 13.12, SD = 7.05; t(111) = 2.082, p < .05$). No other differences between the two samples of patients were identified.

Research Question 3: Are caregivers who participated in the dyadic portion different from those caregivers who did not participate in the dyadic portion?

Chi-square and independent samples t -tests were used to examine differences among unmatched caregivers and caregivers in the dyadic sample (Table 11). There were significantly

more male caregivers in the dyadic sample as compared to the unmatched sample ($\chi^2(1) = 12.336, p < .001$). The dyadic sample was 47.4% male ($n = 9$), while the unmatched sample was only 6.1% male ($n = 2$). Of the nine males in the dyadic sample, one endorsed being a dating partner, six endorsed being a spouse, and two endorsed being a family member of the patient. More than half of the caregivers in the dyadic sample reported being a spouse to the patient, while the independent sample only included 27.3% spouses. The matched sample included four female spouses and six male spouses.

Unmatched caregivers reported providing care for a patient who was younger ($M = 27.79, SD = 6.09$) as compared to those caregivers in the dyadic sample ($M = 31.42, SD = 5.37; t(50) = 2.161, p < .05$). There were more parents as caregivers reported in the unmatched caregivers (36.4%) sample as compared to the matched sample (26.3%).

The type of cancer that the patient had differed between the two samples of caregivers ($\chi^2(7) = 20.423, p < .001$). Only caregivers in the matched sample reported caring for a patient with breast cancer and there were no cases of sarcoma reported in the dyadic sample. Caregivers in the dyadic sample reported hormone replacement therapy more often than caregivers in the unmatched sample, which is likely related to the presence of breast cancer in the dyadic sample. While the type of the cancer differed between the two samples, the type of cancer was not associated with the type of the caregiver in either sample.

The DT was higher among caregivers in the unmatched sample ($M = 6.55, SD = 2.85$) as compared to those caregivers in the dyadic sample ($M = 4.74, SD = 2.50; t(50) = 2.634, p < .05$). Caregivers in the unmatched sample reported a higher PPL score ($M = 20.33, SD = 10.01$) as compared to those in the dyadic sample ($M = 12.68, SD = 7.80; t(50) = 2.862, p < .01$).

Research Question 4: What is the association between distress, coping strategies, and relationship satisfaction among a sample of AYAs with cancer?

Multiple linear regression analysis was used to develop separate models for predicting patients' DT, PPL, and PSS from patients' phase of treatment (e.g., in treatment or in follow up), CSI-EC, CSI-DC and RAS (Table 12) for patients in the unmatched sample. The models also included age and caregiver type as control variables. According to the analyses, lower RAS ($B = -.119, p < .05$) was associated with higher DT among patients ($F(6,75) = 5.420, p < .001$). Being in treatment ($B = -.5.432, p < .01$), higher CSI-DC ($B = .262, p < .01$), and lower RAS ($B = -.272, p < .05$) were associated with a higher PPL ($F(6,75) = 8.739, p < .001$). Higher CSI-DC was associated with higher PSS ($F(6,74) = 6.932, p < .001$).

Research Question 5: What is the association between distress, coping strategies, relationship satisfaction and caregiver burden among a sample of caregivers of young adults with cancer?

Similarly, multiple linear regression analysis was used to develop separate models for predicting caregivers' DT, PPL, and PSS from CSI-EC, CSI-DC, RAS, ZBI and patients' phase of treatment (Table 13) among caregivers in the unmatched sample. The models also included age and caregiver type as control variables. Higher ZBI ($B = .328, p < .05$) was the only predictor significantly associated with a higher PPL ($F(7,35) = 6.168, p < .001$) among caregivers.

Research Question 6: What is the association between dyadic distress and coping strategies among a sample of matched AYA oncology patients and their caregivers?

Of the nine APIM models that accounted for the predictor (CSI-EC, CSI-DC, RAS) and outcome variables (DT, PPL, PSS), three of them included significant partner effects (Table 1).

As this research question aimed to examine how distress and coping are interrelated among patients and their caregivers, partner effects within the APIM provide results for how the patient's predictor is associated with the caregiver's outcome, and vice versa. Model fit was not assessed because all of the models included an equal number of unknown parameters and known parameters (Kenny, Kashy, & Cook, 2006; Kline, 2011). Significant partner effects included: (a) higher caregivers' CSI-EC was associated with lower patients' DT among ($B = -.160, p < .001$), (b) higher caregivers' CSI-EC was associated with lower patients' PPL ($B = -.281, p = .044$), and (c) higher patients' CSI-DC was associated with lower caregivers' PPL ($B = -.489, p = .014$). In addition, two of the nine models included significant actor effects. In one model, significant actor effects included: (a) higher patients' CSI-EC was associated with lower patients' DT ($B = -.160, p < .001$) and (b) higher caregivers' CSI-EC was associated with lower caregivers' DT ($B = -.137, p = .026$). In the other model, significant actor effects included: (a) higher patients' CSI-EC was associated with lower patients' PSS ($B = -.363, p = .001$), and (b) higher caregivers' CSI-EC was associated with lower caregivers' PSS ($B = -.546, p = .002$). Results from the APIM models coping and distress are interrelated among AYA patients and their caregivers.

Discussion

The purpose of this study was to identify the types of caregivers who provide care to AYAs with cancer and examine the association between distress, coping strategies, relationship and caregiver burden among AYA patients and their caregivers. In 2013, LIVESTRONG reported that 82% of the AYAs they served identified a parent as a primary caregiver (Nass & Patlak, 2013). In contrast, this study found that AYA patients relied on a mix of caregivers including parents, friends, dating partners, spouses, and other family members. Parents as caregivers represented less than half of the overall study sample. Younger aged and unmarried

patients were more likely to endorse a parent as a caregiver in the unmatched and dyadic samples. Other AYAs were more likely to endorse a spouse or a dating partner as a caregiver. This finding aligns with normative developmental tasks of emerging adulthood, such as the transition from dependence on the family of origin to independence (Arnett, 2003).

Beyond just identifying that there is significant variability in who AYA oncology patients rely on as a primary caregiver, findings from this study also suggest that there may actually be different groups of caregivers of AYA oncology patients. This study aimed to enroll a dyadic sample of patients and their caregivers, however the partner of some patients and caregivers did not participate in the study. This allowed for the examination of differences among caregivers in the unmatched sample and the dyadic sample. Caregivers in the matched sample were more likely to be male, a spouse, and providing care to a patient with breast cancer. In contrast, the unmatched caregiver sample was primarily female and included a greater portion of parents. These differences support the presence of survey bias.

Approximately one-third of the unmatched caregiver sample were parents. Parents of young adults with cancer parents may not know how to manage the changes in the relationship with their child. The normative developmental tasks of early adulthood include the transition from dependence on the family of origin to independence (Arnett, 2003). Some young adults, who were independent prior to being diagnosed with cancer, may now be dependent on their parents again. These parents may not know how to manage the changes in their relationships while also managing their role as a caregiver (Barling, Stevens, & Davis, 2013) and adjusting to knowing that their child has cancer.

Caregivers in the unmatched sample were significantly more distressed than caregivers in the dyadic sample. In the unmatched sample, caregiver burden was the only predictor significant

in predicting distress. Previous researchers reported that it was the caregiver's subjective experience of being a caregiver and the availability of support that was associated with caregivers' perceived burden (Sternbeg et al., 2010). Some caregivers of AYA patients may not be functioning as well as others. This may be associated with the caregivers' perceived caregiver burden or the relationship dynamics between the caregiver and the patient. Future studies with a variety of caregivers of AYA oncology patients need to evaluate how perceived burden and its associated distress is influenced by ability of the patient and caregiver to engage in a mutually supportive relationship.

The higher distress among the unmatched sample of caregivers may have also been influenced by the higher presence of female participants, as previous researchers have reported that female caregivers as compared to their male counterparts experienced higher levels of distress (Hagedoorn et al., 2008; Hinnen et al., 2009; Hodges et al., 2005; Northouse et al., 2012). As the unmatched sample only included two males, this also raises the concern about the distress and coping strategies of male caregivers. Future studies need to examine how the experience of being a male caregiver compares to the experiences of female caregivers of AYA oncology patients.

The results of the internet-based recruitment approach used in this study may also provide some insight into caregivers' distress. Caregivers who are experiencing high distress and lack a solid relationship with their patient may be more likely to lean on web-based supports to help manage their distress. Future research should evaluate which types of supports caregivers use and consider how the use of those supports (e.g., forums, online support groups, therapy, social contact, relationships, work) is associated with their relationship satisfaction, coping strategies, and distress levels. These caregivers may not be presenting to the cancer center and

may be struggling with their distress in silence. Recruitment through online cancer support groups may have generated more interest by caregivers of younger AYA. Reasons for potential differences are future research opportunities.

Beyond identifying the heterogeneity of caregivers of AYAs with cancer, this study is also the first known to look at distress and coping strategies among AYAs and caregivers of AYAs. This association was examined through analysis with independent samples and with a small dyadic sample. As discussed, the two samples of caregivers enrolled are significantly different and that should be considered in the interpretation of the findings. Findings from the unmatched sample of patients suggest that lower patient-caregiver relationship satisfaction, and greater use of disengagement strategies, was associated with greater patient distress. Previous researchers reported that the use of engagement coping strategies such as emotion and problem-focused strategies were associated with better illness adjustment among young adults with cancer (Kyngas et al., 2001; Miedema et al., 2007; Snöbohm & Heiwe, 2013). An association between relationship satisfaction or disengagement coping strategies and distress has not been previously reported in the literature. These findings support that there is a relational component to patients' distress and should be attended to by healthcare providers, such as Medical Family Therapists. Improving the relationship between patients and their caregivers may help to increase patients' use of engagement coping strategies and reduce their distress. Additional research is needed to understand how the patient-caregiver relationship intersects with the patient's cancer journey, particularly with how the pair manages their distress.

The association of variables was not as strong with the unmatched sample of caregivers. Among caregivers, caregiver burden was associated with an increased number of biopsychosocial and practical problems, which is well supported in the general cancer caregiver

literature (e.g., Bevans & Sternberg, 2012; Grant et al., 2013; Sternberg, Ruland, & Miaskowski, 2010). As discussed above, the caregivers in the unmatched sample were more distressed than those caregivers in the matched sample. The significant association between caregiver burden and distress may also be an indication of the lack of support that the unmatched caregivers experienced. Future researchers should consider whether it is a particular aspect of the burden, such as the financial or practical, that is associated with distress. It would be beneficial to study how relational dynamics mediate the association between burden and distress.

Findings from the sample of matched dyads that were analyzed through an APIM provide additional support for the interrelated nature of distress and coping among AYA patients and their caregivers, something that has not been previously examined. Greater use of engagement coping strategies among caregivers was significantly associated with lower distress among patients. While many AYA patients desire to maintain a sense of normalcy as they go through cancer treatment (Meidema et al., 2007), non-AYA patients reported that they appreciate when they can talk to their family and friends about their fears, concerns, treatment-related issues (Coyne, Wollin, & Creedy, 2012; Synder & Pearse, 2010). Based on the findings from this study, AYA patients also seem to benefit from caregivers who use engagement coping strategies, such as problem solving, expressing emotion, social contact and cognitive restructuring.

Results from the APIM models support the effect of patients' use of coping strategies on caregivers' distress. Greater use of disengagement coping strategies by patients was significantly associated with a lower score on the Patient Problem List by caregivers. Previously researchers reported that negative coping strategies, such as disengagement, were associated with increased dyadic distress (Badr et al., 2010; Feldman & Broussard, 2006; Lafaye et al., 2014; Manne et al., 2010; Rottmann et al., 2015); however, findings from this study suggest that this may not apply

to AYAs and their caregiver. This may be associated with caregivers' confidence in their role, which has been previously reported to be associated with the severity of the patient's symptoms, availability of additional support and the quality of their relationship with the patient (Barling et al., 2013). If patients are using disengagement strategies such as problem avoidance, wishful thinking, and social withdrawal, then caregivers may not be aware of the severity of the patient's symptoms or assuming that the patient is adjusting better than he or she really is. If the caregiver thinks that the patient is doing well, then they may be less likely to feel distressed.

It is important to note the dyadic sample included a high percentage of breast cancer patients and spousal caregivers and thus may not be generalizable to the entire AYA patient-caregiver population. Future studies should consider how to capture the dyadic experience of distress and coping with caregivers who are not as engaged with their patient. Recruiting this type of sample may be best done through in-person recruitment and community based approaches (Northouse et al., 2006)

Despite the limited generalizability of the findings from the APIM analysis, overall the findings from this study support the use of the systemic transactional model (STM; Bodenmann, 1995, 2005) for examining the interrelated nature of distress and coping among AYA oncology patients and their caregivers. Higher levels of relationship satisfaction was associated with lower distress among unmatched patients. While relationship satisfaction was not significant among caregivers, there were significant differences in distress between unmatched and matched patients which suggests that there may be a relational factor associated with their distress. Furthermore, there were significant actor and partner effects that were identified through the APIM analysis.

Previous researchers who examined the dyadic nature of distress and coping among non-AYA cancer patients and their caregiver through STM noted that positive coping, such as engagement coping strategies, was associated with better adjustment in a dyadic model (Badr et al., 2010; Badr & Carmack Taylor, 2008; Lafaye et al., 2014; Manne et al., 2010); however, a direct relationship between positive coping and distress has not been previously noted in the general oncology literature (Feldman & Broussard, 2006; Manne et al., 2010; Traa et al., 2015). The caregivers of AYAs, such as parents or spouses, may not be comfortable in their caregiver role and may benefit from patients' use of problem-solving and emotion expression. Future qualitative and quantitative research is needed to expand the knowledge base regarding dyadic nature of distress and coping among AYAs and their caregivers by expanding the number of dyads and diversity of caregiver types. STM serves as a valuable foundation for building this knowledge base. Understanding what patients need from their caregivers is valuable to healthcare providers working with this patient population as they can provide targeted interventions to help nurture the relationship between patients and their caregivers.

Implications

This study provides evidence to suggest that patient-caregiver relationship satisfaction is important to patients' distress and that the use of engagement and disengagement coping strategies do influence patients' and caregivers' acute and overall distress. This information is particularly useful to healthcare providers, researchers, and program developers who aim to understand and meet the psychosocial needs of AYAs with cancer. While attending to patients' needs is the priority for most healthcare providers, findings from this study suggest that attending to caregivers' needs is also important. Caregivers' distress and coping strategies are closely connected to patients' distress and coping strategies, thus provide another layer through which

healthcare providers can provide support. Healthcare providers can utilize this information to help connect patients with therapy or other psychosocial support as needed. Attending to caregivers' distress and increasing their ability to manage their caregiver burden and use of engagement coping strategies may indirectly reduce patients' distress. As well, findings from this study suggest that the patient's perception of their relationship with the caregiver is associated with patients' acute distress, as higher relationship satisfaction was associated with lower distress. Thus, clinicians attending to the treatment of the physical problems of cancer should also attend to the quality of the relationship between patients and their caregivers. Clinicians may want to consider how to help nurture the relationship between AYA patients and their caregivers in efforts to reduce patients' distress.

A large portion of research about AYA patients' experience of cancer has been limited to data collected from only the patient (e.g., Patterson, McDonald, Zebrack, & Medlow, 2015; Trevino et al., 2012; Yanez et al., 2013) and very few studies have aimed to incorporate patients' caregivers (Juth et al., 2015). This is despite recognition by researchers that friends and family are important to patients' cancer experiences (e.g., Bellizzi et al., 2012; Carpentier & Fortenberry, 2010; Decker, 2007; Enskär & von Essen, 2007; Goodall, King, Ewing, Smith, & Kenny, 2012; Miedema et al., 2007; Zebrack, 2011; Zebrack et al., 2006). Findings from this study highlight the need for researchers to increase their attention to the caregivers of AYAs as they may be experiencing higher levels of distress than the patients. The use of STM (Bodenmann, 1995, 2005) for including caregivers, and other members of the patient's support system, in future studies is valuable to understanding AYA patients' experiences. As STM posits, when a dyad, such as the patient-caregiver dyad, is faced with a shared stressor, the pair cope

both individually and jointly (Bodenmann, 1995, 2005). Findings from this study support this claim and bring attention to the need for more research about the caregivers of AYAs.

Shifting from the individual perspective and embracing a more systemic research approach will provide researchers valuable insight to the complexity of patients' lived experiences. As AYA-specific cancer centers and programs continue to develop (Reed et al., 2014), findings from this study provide support for the need to consider whether a family-centered approach to care, which is commonly utilized in pediatric settings (e.g., Holm, Patterson, & Gurney, 2003), is a better fit for addressing the AYAs' inter- and intrapersonal needs. Embracing a relational or family-centered approach to AYAs with cancer by including their caregivers will support the field's goals of improving survival rates and addressing unmet needs (AYAO PRG, 2006).

Limitations

Although this study provided preliminary support for the application of the STM (Bodenmann 1995, 2005) for examining how coping and distress are related among AYA patients and their caregivers, there are several limitations to note. The use of an online recruitment approach may have led to survey bias present in this study. While patients and caregivers had the option to enter the email address of their dyad partner, some participants chose not to. Of the 113 patients that enrolled in the study, only 39 of them included an email address for their caregiver. This raises the question about why the other 74 did not want to invite their caregiver to participate in the study. It is also unclear whether all of the emailed invitations were received and read. Furthermore, they may have been some invited individuals who chose to not participate. This lack of clarity speaks to the challenges of recruiting a dyadic sample through an online approach. Other recruitment approaches, such as recruiting at a cancer clinic, may have

yielded a large sample of dyads. With this limitation, however, 19 dyads did demonstrate support for the dyadic nature of distress and coping among young adults with cancer and their caregivers.

Both the patient sample and the caregiver sample lacked racial and ethnic diversity. This may be reflective of the web-based recruitment strategies employed. However, the research team contacted racially and ethnically diverse Facebook groups and twitter accounts to increase the odds of having a diverse participant pool. Including a greater portion of racially and ethnically diverse participants is important for understanding if the type of caregiver is associated with racial and ethnic differences.

This study utilized self-reported responses for outcomes and predictors, which means there was no way to validate participants' responses. As well, the measures were collected cross-sectionally so it is not possible to determine the causal nature of distress and coping among AYA patients and their caregivers. Longitudinal studies could further clarify the relationship between the constructs, which is valuable for developing interventions and resources. Future studies would also benefit from including duration since treatment completion as this may predict distress and coping choices (Millar, Patterson, & Desille, 2010).

Another limitation to recognize is that there were only 19 dyads enrolled in the study. This limits the generalizability of the results identified through the APIM models. The small number of matched dyads may be a reflection of the recruitment strategies or may potentially highlight some of the relational dynamics that are present in AYA patient-caregiver relationships. While it was a small dyadic sample of matched participants, it is the first study to capture dyadic level data from AYA patients and their caregivers. Previous researchers have examined distress among non-AYA cancer patient-caregiver dyads with sample sizes as small as 15 dyads (Kaye & Gracely, 1993).

Conclusion

This innovative study approach provides original findings examining the interrelated nature of distress and coping among young adults cancer patients and their caregivers. As AYAs face cancer, they rely on a variety of caregivers including parents, spouses, friends and others in their support system. This study provides valuable knowledge about who the caregivers of young adults are and supports that the caregivers of young adults experience distress. Some caregivers of AYAs may actually experience more distress than others and this may be associated with relational dynamics. As healthcare providers, researchers, and program developers aim to meet to the needs of the patient, attending to relational dynamics may provide valuable insight to the psychosocial needs of AYA patients.

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Table 1

*Demographic Characteristics for Independent Samples of Patients and**Caregivers.*

Characteristic	Patients* (n=94)	Caregivers* (n=33)
	Frequency (%) or Mean (SD)	
Current age	30.89 (5.65)	38.12 (13.38)
Age of caregiver as reported by patient	43.72 (12.58)	
Age of patient as reported by caregiver		27.79 (6.09)
Gender		
Male	19 (20.2)	2 (6.1)
Female	75 (79.8)	31 (93.9)
Sexual Orientation		
Heterosexual	86 (91.5)	30 (90.3)
Lesbian or Gay	3 (3.2)	1 (3.0)
Bisexual	2 (2.1)	2 (6.1)
Other	3 (3.2)	
Race		
Caucasian/White	83 (88.3)	31 (93.9)
African-American/Black	2 (2.1)	
Asian/Pacific-Islander	4 (4.3)	
American Indian/Alaskan Native	2 (2.1)	
Bi-racial	2 (2.1)	
Multi-racial	1 (1.1)	1 (3.0)
Other		1 (3.0)
Ethnicity		
Hispanic	4 (4.3)	4 (12.5)
Not Hispanic	88 (95.7)	28 (87.5)
Country of Origin		
USA	89 (94.7)	30 (90.9)
Outside of USA	5 (5.3)	3 (9.1)
Highest level of education completed		
High school diploma	5 (5.3)	1 (3.0)
Some college	20 (21.3)	9 (27.3)
Associate degree	10 (10.6)	5 (15.2)
Bachelor's degree	24 (25.5)	13 (39.4)
Master's degree	27 (28.7)	4 (12.1)
Professional degree (MD, DDS)	4 (4.3)	1 (3.0)
PhD	3 (3.2)	
Other	1 (1.1)	

(Table 1 continued)

Annual household income		
\$0 - \$50,000	34 (36.6)	12 (38.7)
\$50,001 - \$100,000	33 (35.5)	12 (38.7)
\$100,001+	26 (28.0)	7 (22.6)
<hr/>		
Current relationship status		
Single	16 (17.0)	2 (6.1)
Dating	25 (26.6)	2 (6.1)
Cohabiting	11 (11.7)	5 (15.2)
Married	50 (42.6)	21 (63.6)
Divorced	2 (2.1)	1 (3.0)
Widowed		2 (6.1)
<hr/>		
Caregiver Relationship to patient		
Parent	30 (32.6)	12 (36.4)
Friend		1 (3.0)
Partner	17 (18.5)	8 (24.2)
Spouse	33 (35.9)	9 (27.3)
Family member	9 (9.8)	3 (9.1)
None	2 (2.2)	

* Numbers do not sum to totals due to missing numbers

Table 2

Demographic Characteristics for the Matched Sample of Patients and Caregivers.

Characteristic	Patients*	Caregivers*
	Frequency (%) or Mean (SD)	
Current age	31.32 (5.35)	40.68 (11.82)
Gender		
Male	5 (26.3)	9 (47.4)
Female	14 (73.7)	10 (52.6)
Race		
Caucasian/White	17 (89.5)	15 (78.9)
Asian/Pacific Islander	1 (5.3)	1 (5.3)
Multi-racial		1 (5.3)
Other	1 (5.3)	2 (10.5)
Ethnicity		
Hispanic	2 (11.1)	2 (10.5)
Not Hispanic	16 (88.9)	17 (89.5)
Highest level of education completed		
Some high school		1 (5.3)
High school diploma		1 (5.3)
Some college	4 (21.1)	4 (21.1)
Associate degree	1 (5.3)	2 (10.5)
Bachelor's degree	5 (26.3)	7 (36.8)
Master's degree	7 (36.8)	3 (15.8)
PhD	1 (5.3)	
Other	1 (5.3)	1 (5.3)
Annual household income		
\$0 - \$50,000	10 (52.6)	6 (33.3)
\$50,001 - \$100,000	7 (38.9)	9 (50.0)
\$100,001+	1 (5.6)	3 (16.7)
Current relationship status		
Single	4 (21.1)	1 (5.3)
Dating	2 (10.5)	1 (5.3)
Cohabiting	2 (10.5)	3 (15.8)
Married	10 (52.6)	14 (73.7)
Divorced	1 (5.3)	
Caregiver relationship to patient		
Parent		5 (26.3)
Partner		2 (10.5)
Spouse		10 (52.6)
Family member		2 (10.5)

Note. N=19

* Numbers do not sum to totals due to missing numbers

Table 3

Clinical Characteristics for Independent Samples of Patients and Caregivers as Reported by Patients and Caregivers, Respectively.

Characteristic	Patients*	Caregivers*
	(n=94)	(n=33)
	Frequency (%) or Mean (SD)	
Cancer Type		
Lymphoma	27 (28.7)	7 (21.9)
Leukemia	9 (9.6)	4 (12.5)
Sarcoma	2 (2.1)	9 (28.1)
Breast	24 (25.5)	
Cervical	6 (6.4)	
Thyroid	8 (8.5)	
Melanoma		2 (6.3)
Testicular	3 (3.2)	5 (15.6)
Colorectal	4 (4.3)	1 (3.1)
Other	11 (11.7)	4 (12.5)
Treatments received (more than one option could be selected)		
Surgery	65 (69.1)	20 (60.6)
Chemotherapy	80 (85.1)	31 (93.9)
Radiation	40 (42.6)	10 (30.3)
Bone Marrow/Stem Cell Transplant	10 (10.6)	4 (12.1)
Hormone Replacement Therapy	21 (22.3)	1 (3.0)
Current treatment state		
Active	35 (37.6)	15 (46.9)
Follow-up	58 (62.4)	15 (46.9)
Don't know		2 (6.3)

* Numbers do not sum to totals due to missing numbers

Table 4

Clinical Characteristics of Patients Included in the Matched Sample of Patients and Caregivers, as Reported by the Patient.

Characteristic	Frequency (%)
Cancer Type	
Lymphoma	3 (15.8)
Leukemia	3 (15.8)
Breast	7 (36.8)
Testicular	1 (5.3)
Colorectal	1 (5.3)
Other	4 (21.1)
Treatments received (more than one option could be selected)	
Surgery	11 (57.9)
Chemotherapy	15 (78.9)
Radiation	7 (36.8)
Bone Marrow/Stem Cell Transplant	2 (10.5)
Hormone Replacement Therapy	5 (26.3)
Treatment at a Pediatric or Adult Setting	
Pediatric	3 (15.8)
Adult	16 (84.2)
Current treatment state	
Active	8 (42.1)
Follow-up	11 (57.9)

Note. N=19

Table 5

Mean Differences in Measures of Distress, Coping, Relationship Satisfaction and Caregiver Burden for Patients and Caregivers in the Independent Samples of Patients and Caregivers, as Reported by Patients and Caregivers, Respectively.

Measures	Patients (n=94)	Caregivers (n=33)	<i>t</i> ^a	<i>df</i>	<i>p</i> -value
	Mean (SD)				
Outcome measures:					
Distress Thermometer (range 0 – 10)	4.89 (2.44)	6.55 (2.85)	2.948	56.276	.005**
Patient Problem List (range 0 – 39)	13.12 (7.05)	20.33 (10.01)	3.697	50.501	.001**
Perceived Stress Scale (range 0 – 40)	20.04 (7.02) ^c	21.97 (6.51) ^d	1.098	123	.274
Predictors:					
Coping - engagement (range 0 – 64)	54.62 (11.48) ^e	50.48 (12.88) ^f	1.239	115	.218
Coping - disengagement (range 0 – 64)	41.01 (11.11) ^e	41.31 (11.89) ^f	.256	115	.799
Relationship Assessment Scale (range 7 – 35)	30.29 (5.34) ^e	29.07 (4.36) ^c	.789	114	.432
Zarit Burden Inventory (range 0 – 88)		32.41 (16.10)			

** $p < .01$

^aIndependent samples *t*-test

^bThe Zarit Burden Inventory was only completed by caregivers.

^cMissing data for 5 cases

^dMissing data for 1 case

^eMissing data for 8 cases

^fMissing data for 4 cases

^gMissing data for 6 cases

Table 6

Mean Differences in Measures of Distress, Coping, and Relationship Satisfaction for Patients and Caregivers in the Matched Sample of Patients and their Caregivers, as Reported by Patients and their Caregivers.

Measures	Patients	Caregivers	t^a	df	p value
	Mean (SD)				
Outcome measures:					
Distress Thermometer (range 0 – 10)	5.16 (2.41)	4.74 (2.50)	1.006	18	.328
Patient Problem List (range 0 – 39)	16.84 (7.32)	12.68 (7.80)	1.774	18	.093
Perceived Stress Scale ^b (range 0 – 40)	20.59 (6.29)	18.37 (8.23)	1.504	16	.152
Predictors:					
Coping – engagement ^c (range 0 – 64)	50.37 (10.11)	50.28 (9.42)	.016	15	.987
Coping – disengagement ^c (range 0 – 64)	42.56 (8.74)	38.67 (8.93)	1.078	15	.298
Relationship Assessment Scale ^b (range 7 – 35)	28.82 (6.72)	30.26 (3.53)	1.014	16	.326

Note. N=19

^aPaired samples *t*-test

^bMissing data for 2 cases

^cMissing data for 3 cases

Table 7

Correlations Between Measures of Distress, Coping, Relationship Satisfaction, and Caregiver Burden for Independent Samples of Patients (above the diagonal) and Caregivers (below the diagonal).

	1	2	3	4	5	6
Outcomes measures:						
1. Distress Thermometer		.580**	.561**	-.443**	.422**	-.385**
2. Patient Problem List	.659**		.745**	-.352**	.486**	-.326*
3. Perceived Stress Scale	.595**	.627**		-.485**	.541**	-.386**
Predictors:						
4. Coping - engagement	-.280	-.345	-.504**		-.494**	.348*
5. Coping - disengagement	.370	.548**	.504**	-.294		-.370**
6. Relationship Assessment Scale	-.199	-.355	-.189	.141	-.015	
7. Zarit Burden Inventory ^a	.280	.693**	.391*	-.283	.421*	-.672**

Note. Patients (n=94) above the diagonal; Caregivers (n=33) below the diagonal

* $p < 0.05$

** $p < 0.01$

^aOnly caregivers completed the Zarit Burden Inventory

Table 8

Correlations Between Measures of Distress, Coping, Relationship Satisfaction, and Caregiver Burden

Separately for Patients (above the diagonal) and Caregivers (below the diagonal) in the Matched

Sample.

	1	2	3	4	5	6
Outcome measures:						
1. Distress Thermometer		.326	.540*	-.569*	.431	-.406
2. Patient Problem List	.847**		.550*	-.310	.328	.143
3. Perceived Stress Scale	.765**	.826**		-.564*	.434	-.563*
Predictors:						
4. Coping - engagement	-.494*	-.411	-.644**		-.662**	.100
5. Coping - disengagement	.117	.285	.370	-.328		-.335
6. Relationship Assessment Scale	-.204	-.023	-.151	.348	-.110	
7. Zarit Burden Inventory ^a	.690**	.692**	.794**	-.514*	.508*	-.277

Note. N=19

* p < 0.05

** p < 0.01

^aOnly caregivers completed the Zarit Burden Inventory

Table 9

Correlations Between Measures of Distress, Coping, Relationship Satisfaction, and Caregiver Burden Between Patients (top) and Caregivers (left) in the Matched Sample.

	1	2	3	4	5	6
Outcome measures:						
1. Distress Thermometer	.272	.156	.345	-.051	-.382	.012
2. Patient Problem List	.236	.089	.229	.078	-.504*	.018
3. Perceived Stress Scale	.247	.207	.496*	.053	-.391	-.175
Predictors:						
4. Coping - engagement	-.326	-.410	-.241	-.201	.295	.265
5. Coping - disengagement	-.003	-.133	.064	.041	.002	-.109
6. Relationship Assessment Scale	-.442	-.087	-.537*	.480	-.354	.578*
7. Zarit Burden Inventory ^a	.152	.246	.473	.013	-.257	-.259

Note. N=19

* $p < 0.05$

^aOnly caregivers completed the Zarit Burden Inventory

Table 10

Mean Differences in Ages, Measures of Distress, Coping, and Relationship Satisfaction for Patients in the Unmatched and Matched Samples.

Measures	Unmatched (n=94)	Matched (n=19)	<i>t</i> ^a	<i>df</i>	<i>p</i> -value
	<i>Mean (SD)</i>				
Age	30.89 (5.65)	31.32 (5.35)	.300	111	.765
Caregiver's age	43.72 (12.58) ^b	40.63 (11.96)	.981	107	.329
Outcome measures:					
Distress Thermometer (range 0 – 10)	4.89 (2.45)	5.16 (2.41)	.430	111	.668
Patient Problem List (range 0 – 39)	13.12 (7.05)	16.84 (7.32)	2.082	111	.040*
Perceived Stress Scale (range 0 – 40)	20.04 (7.02) ^c	20.75 (6.46) ^d	.374	103	.709
Predictors:					
Coping – engagement (range 0 – 64)	54.62 (11.48) ^e	50.38 (9.42) ^d	1.380	100	.171
Coping – disengagement (range 0 – 64)	41.01 (11.11) ^e	42.56 (8.74) ^d	.528	100	.599
Relationship Assessment Scale (range 7 – 35)	30.29 (5.34) ^e	28.76 (6.69) ^f	1.031	101	.305

* $p < .05$

^aIndependent samples *t*-test

^bMissing data for 4 cases

^cMissing data for 5 cases

^dMissing data for 3 cases

^eMissing data for 8 cases

^fMissing data for 2 cases

Table 11

Mean Differences in Ages, Measures of Distress, Coping, Relationship Satisfaction, and Caregiver Burden for Caregivers in the Unmatched and Matched Samples.

Measures	Unmatched (n=33)	Matched (n=19)	<i>t</i> ^a	<i>df</i>	<i>p</i> -value
	<i>Mean (SD)</i>				
Age	38.12 (13.38)	40.68 (11.82)	.693	50	.491
AYA's age	27.79 (6.09)	31.42 (5.37)	2.161	50	.036*
Outcome measures:					
Distress Thermometer (range 0 – 10)	6.55 (2.85)	4.74 (2.50)	2.634	50	.011*
Patient Problem List (range 0 – 39)	20.33 (10.01)	12.68 (7.80)	2.862	50	.006**
Perceived Stress Scale (range 0 – 40)	21.97 (6.51) ^b	18.37 (8.23)	1.728	49	.090
Predictors:					
Coping – engagement (range 0 – 64)	50.48 (12.88) ^c	50.28 (9.42) ^b	.058	45	.954
Coping – disengagement (range 0 – 64)	41.31 (11.89) ^c	38.67 (8.94) ^b	.990	45	.422
Relationship Assessment Scale (range 7 – 35)	29.07 (4.36) ^d	30.26 (3.52)	.789	45	.327
Zarit Burden Inventory (range 0 – 88)	32.41 (16.10) ^e	25.90 (13.31)	1.448	44	.155

* $p < .05$

** $p < .01$

^aIndependent samples *t*-test

^bMissing data for 1 case

^cMissing data for 4 cases

^dMissing data for 5 cases

^eMissing data for 6 cases

Table 12

Patients' Distress Thermometer (Model 1), Patient Problem List (Model 2), and Perceived Stress Scale (Model 3) as Predicted by Treatment Phase, Use of Coping Strategies, and Relationship Satisfaction in the Independent Sample of Patients.

Measures	Model 1			Model 2			Model 3		
	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β
Predictors:									
Treatment Phase	-.994	.494	-.188	-5.432	1.300	-.378**	-1.646	1.374	-.113
Coping - engagement	-.046	.025	-.205	-.055	.066	-.086	-.118	.069	-.183
Coping - disengagement	.050	.026	.224	.262	.067	.405**	.266	.070	.414**
Relationship Assessment Scale	-.119	.050	-.247*	-.272	.132	-.197*	-.234	.138	-.169
Control variables:									
Age	.019	.050	.044	.236	.114	.190*	.111	.121	.088
Type of caregiver	-.166	.128	-.129	-.066	.338	-.018	-.123	.355	-.033
<i>F</i>		5.420**			8.739**			6.932**	
<i>R</i> ²		.302			.411			.360	

Note. *N*=94, *B* = unstandardized coefficient, *SE B* = standard error of unstandardized coefficient, β = standardized coefficient.

**p* < .05

***p* < .01

Table 13

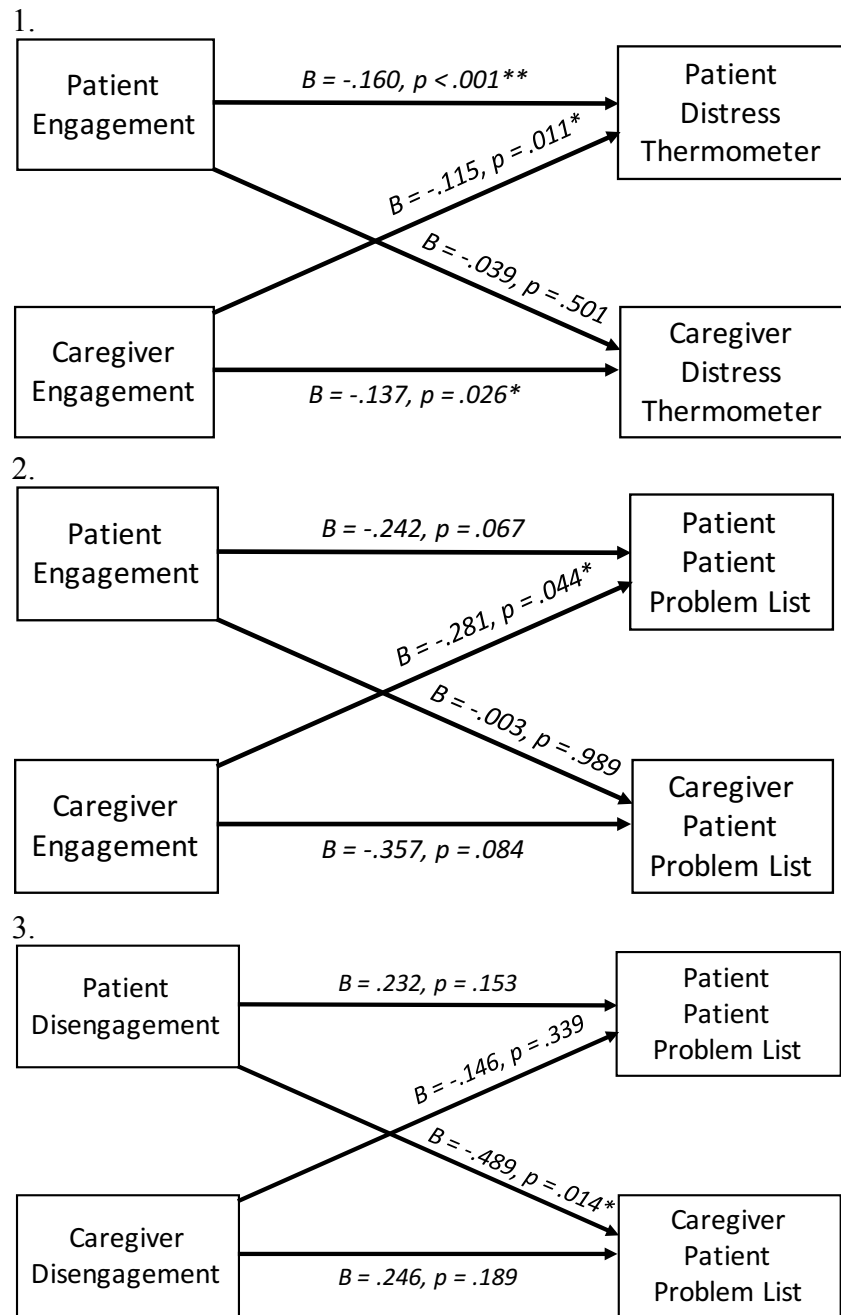
Caregivers' Patient Problem List Predicted by Treatment Phase, Use of Coping Strategies, Relationship Satisfaction and Caregiver Burden.

Measures	<i>B</i>	<i>SE B</i>	β
Predictors:			
Treatment Phase	-1.727	3.351	-.106
Coping - engagement	-.197	.145	-.247
Coping - disengagement	.184	.133	.237
Relationship Assessment Scale	.143	.474	.065
Zarit Burden Inventory	.328	.141	.522*
Control variables:			
Age	-.137	.141	-.205
Type of caregiver	-1.034	1.255	-.824
<i>F</i>		4.269**	
<i>R</i> ²		.637	

Note. N=33, *B* = unstandardized coefficient, *SE B* = standard error of unstandardized coefficient, β = standardized coefficient.

***p* < .01

Figure 1. Actor-partner interdependence models for: (1) engagement coping and distress scores, (2) engagement coping and patient problem list, and (3) disengagement coping and patient problem list among 19 patient-caregiver dyads



CHAPTER SIX: IMPLICATIONS

Stagnant survival rates (Bleyer & Barr, 2009; Bleyer et al., 2009; Soliman & Agresta, 2008) and complex psychosocial needs (Dyson, Thompson, Palmer, Thomas, & Schofield, 2012; Keegan et al., 2012; Smith et al., 2013; Zebrack et al., 2013; Zebrack et al., 2014) among Adolescent and Young Adult (AYA) oncology patients (ages 15 - 39) point to a population deserving of advancements in research and clinical care. Meeting this patient 's needs has recently grown in focus as AYA-specific programs have opened nationally and research with this population has grown (e.g., Dyson et al., 2012; Keegan et al., 2012; Keegan et al., 2014; Reed, Block, & Johnson, 2014; Smith et al., 2013; Zebrack et al., 2013, 2014). Understanding how cancer uniquely impacts this population may be understood through examining the theory of emerging adulthood (Arnett, 2000, 2003), a developmental theory that helps appreciate how normative milestones (e.g., gaining independence from parents) may be complicated by non-normative events (e.g., cancer). This dissertation was conducted to help expand the body of research with the AYA population, while keeping in mind the biomedical, psychological, social, spiritual, and practical strengths and challenges for AYA patients and their caregivers may face.

While the expansion of AYA research is impressive, many of the efforts have been specifically targeted to the individual patient, rather than from a relational or systemic lens; thereby, limiting the understanding of oncological disease to the individual patient's experience or perceptions (e.g., Bellizzi et al., 2012; Enskär & von Essen, 2007; Miedema et al., 2007; Zebrack, 2011). Very few life events occur in isolation (Von Bertalanffy, 1968), whether the event is a rite of passage (e.g., a wedding) or a mundane but necessary task (e.g., grocery shopping). As such, research that is done to investigate the care of patients without considering how the cancer impacts the patient and those around him or her is very limited in its applicability

(Von Bertalanffy, 1968). The purpose of this chapter is to review the findings of the previous articles (chapters 2 and 5) in this dissertation regarding AYA oncology, and provide clinical, research, and policy implications based on these findings.

Chapters two and five expanded the lens of research with AYA oncology patients to a systemic (chapter 2) and relational (chapter 5) level. The systematic review (chapter 2) was guided by intersectionality theory (Crenshaw, 1989, 1991, 1995). Intersectionality theory is a framework that supports examining how the experiences of patients, families, and communities are shaped by the intersection of multiple social locations or sociodemographic factors (e.g., age, gender, race/ethnicity, sexual orientation; Crenshaw, 1989, 1991, 1995). The systematic review, which included 42 studies, identified sociodemographic variables associated with disparities in incidence and mortality rates, access to care and unmet supportive care needs experienced by AYA oncology patients. The findings suggested that older AYAs (Denslow et al., 2012; Holmes et al., 2008; Kent, Sender, Largent, & Anton-Culver, 2009), non-White AYAs (Desantis, Jemal, & Ward, 2010; Joslyn, Foote, Nasser, Coughlin, & Howe, 2005; Kent et al., 2010), those without private insurance (Aizer et al., 2014; Robbins et al., 2014; Smith et al., 2012), those who live in a lower SES neighborhoods (Kent et al., 2010; Smith et al., 2012), those who were not treated in the Northeast region of the United States (Robbins et al., 2014), and individuals who were unmarried (Kent et al., 2010) had the worst outcomes related to incidence and mortality. Recognizing and addressing the additional disparities faced by some AYA oncology patients is necessary in reducing the overall stagnation of survival rates among the AYA patient population (Bleyer et al., 2009; Bleyer, Viny, & Barr, 2006; Tai et al., 2012).

As compared to studies that assessed incidence and mortality among AYAs, there were significantly fewer studies that examined some aspect of access to care among AYA oncology

patients and non-patients seeking cancer screenings (see chapter 2). The length of time to a diagnosis or beginning treatment, receiving definitive therapy and receiving ongoing medical care among AYAs was associated with being younger (Aizer et al., 2014; Robbins et al., 2014), not White (Aizer et al., 2014; Keegan et al., 2014; Parsons, Harlan, Seibel, Stevens, & Keegan, 2011; Robbins et al., 2014), unmarried (Aizer et al., 2014), living in low SES neighborhood (Robbins et al., 2014), and not having private insurance (Aizer et al., 2014; Keegan et al., 2014; Martin et al., 2007). Similarly, higher unmet health and supportive care needs were associated with being not White, not employed and having a lower level of education (Keegan et al., 2012; Zebrack, 2008, 2009; Zebrack et al., 2013; Zebrack, Mills, & Weitzman, 2007). Some AYA patients are at additional risk for delays in accessing caring and having their supportive care needs met. While the biomedical and psychosocial needs of AYA patients are recognized as being different from pediatric and adult populations (Adolescent and Young Adult Oncology Progress Review Group, 2006; Nass & Patlak, 2013), additional efforts to further understand within group differences would be beneficial to improving the quality of care for all AYA patients.

Overall the findings in chapter two indicate that there are multiple sociodemographic variables associated with disparities in the incidence of and mortality from cancer, access to screening, treatment and post-cancer care, as well as unmet health and supportive care needs. This review highlights the need for studies focusing on understanding the disparities experienced by AYA oncology patients, and how those disparities are associated with the intersection of age, gender, ethnicity, sexual orientation, ability, nation of origin, and socioeconomic status. It raises the importance of attending to patients' experiences from a systemic lens, such as intersectionality theory (Crenshaw, 1989, 1991, 1995), rather than assuming that the experience

is not influenced by larger social issues.

The second research article (chapter 5), guided by the systemic transactional model (STM; Bodenmann, 1995, 2005), examined the interconnectedness of patients' and caregivers' distress and coping. Findings from the second article provided preliminary evidence that distress and coping strategies are interrelated among AYA patients and their caregivers and support the application of STM to this population. This was discovered through a descriptive, cross-sectional survey study that aimed to identify who the caregivers of young adults with cancer are and what the association between distress and coping are among patients and caregivers. Outcome measures included: (a) the Distress Thermometer (DT; Roth et al., 1998), (b) the Patient Problem List (PPL; Roth et al., 1998), and the (c) Perceived Stress Scale (PSS; Cohen, Kamarck, & Mermelstein, 1983). The DT and PPL served as indicators of acute distress, while scores from the PSS provided an overall measure of stress. Predictor measures included: (a) the Coping Strategies Inventory (CSI; Tobin, Holroyd, Reynolds, & Wigal, 1989), (b) the Relationship Assessment Scale (RAS; Hendrick, 1988; Hendrick, Dicke, & Hendrick, 1998), and (c) caregivers also completed the Zarit Burden Inventory (ZBI; Zarit, Reever, & Bach-Peterson, 1980). The sample for this study included a mix of caregivers including parents, dating partners, spouse and non-parent family members, as well as two participants who reported not having a caregiver. Patients who were younger and unmarried were more likely to endorse a parent as a caregiver in the unmatched and dyadic samples. Older AYAs were more likely to endorse a spouse or a dating partner as a caregiver.

Beyond just identifying that there is significant variability in who AYA oncology patients rely on as a primary caregiver, findings from chapter five also highlight that there may be different groups of caregivers of AYA oncology patients. While the study aimed to enroll a

dyadic sample of patients and their caregivers, the partners of some patients and caregivers did not participate. Of the 113 patients that enrolled in the study, only 39 of them included an email address for their caregiver. This raises the question about why the other 74 did not want to invite their caregiver to participate in the study. This was similar with the caregiver sample as well. Of the 56 caregivers who participated, only 17 included an email address for the patient. This raises the questions about why the other 39 did not invite the patient to participate in the study.

Furthermore, there were only 19 dyads enrolled, so this raises the question about why some individuals chose not to participate after they were invited. The response bias suspected here may be associated with clinical (e.g., type of cancer, treatment) or with relational characteristics. Stress can be experienced within a dyad in several ways, including that: (a) it only impacts one partner, (b) it directly impacts one partner and indirectly impacts the other, and (c) it impacts both partners (Bodenmann, 1995, 2005). Participants' decision to not include the email address of their dyad partner may be associated with how stress is being experienced by members of the dyad. These participants may be worried that by inviting the other dyadic member they are going to cause their partner additional distress. These participants may not feel as connected to their dyadic partner and may not be ready to recognize the dyadic nature of distress.

The results of this recruitment approach allowed for the examination of differences among caregivers in the unmatched sample and the matched sample of patient and caregiver dyads. In the matched sample there were more male caregivers ($n=9$), spousal caregivers ($n=10$), and patients with breast cancer ($n=7$). In contrast, the unmatched caregiver sample was primarily female and included a greater portion of parents. The presence of more females may be associated with the gender differences in emotional expression among men and women (Notarius & Johnson, 1982; Zakowski et al., 2003). Women's emotional well being is more

affected by the well-being of others as compared to men's emotional well-being (Notarius & Johnson, 1982; Zakowski et al., 2003). Female caregivers may be more likely to reach out to a variety of support systems in getting their needs met.

Caregivers in the unmatched sample were significantly more distressed than caregivers in the dyadic sample. In the unmatched sample, caregiver burden was the only predictor significantly associated with distress. Higher reports of caregiver burden were associated with higher PPL scores. Caregivers struggling to manage their caregiving responsibilities may not have the capacity to attend to their own well-being. Previous researchers reported that it may be the caregiver's subjective experience of being a caregiver and the availability of support to the caregiver was associated with caregivers' perceived burden (Stenberg, Ruland, & Miaskowski, 2010). Some caregivers of AYA patients may not be functioning as well as others. This may be associated with the caregivers' perceived caregiver burden or the relationship dynamics between the caregiver and the patient. These findings may indicate whereas the supportive nature of the relationship between patients and caregivers could be serving to buffer the dyadic nature of the distress, matched caregivers may also have more available resources for managing their distress. If patients or caregivers are reporting high PPL scores, healthcare providers should consider how relational dynamics may influence their report of symptoms or problems. Recognizing the interconnected nature of distress and coping among patients and caregivers is posited by STM (Bodenmann, 1995, 2005) and supported through findings from this dissertation.

Beyond identifying the types of caregivers present, the study in chapter five also examined the association between distress and coping strategies among AYA patients and caregivers of AYA patients, as guided by the STM (Bodenmann, 1995, 2005). This association was examined through analysis with independent samples of patients and caregivers, as well as a

small dyadic sample of patients and their caregivers. Multiple linear regression analyses were conducted to examine how patients and caregivers use of engagement (e.g., problem solving, social contact) and disengagement (e.g., social withdrawal, problem avoidance) coping strategies, relationship satisfaction, and caregiver burden (for caregivers only) were associated with distress, presence of problems, and perceived stress. Among patients, lower patient-caregiver relationship satisfaction and greater use of disengagement strategies were associated with greater distress. Understanding the association between coping and distress among AYA oncology patients and their caregivers provides healthcare providers a framework through which to increase patients' and caregivers' abilities to manage the stresses of cancer treatment. Early interventions for managing distress should lead to better short-term and long-term psychosocial outcomes for this patient population (Kwak et al., 2013).

Findings from chapter five highlight that the AYA patient-caregiver relationship is important to helping AYA patients manage their distress. Higher relationship satisfaction was associated with lower DT and PPL scores among patients, suggesting their relationship with the caregiver may serve as a buffer from distress. AYA oncology patients repeatedly have reported that relationships with family and friends are important sources of support during their cancer experiences (e.g., Bellizzi et al., 2012; Carpentier & Fortenberry, 2010; Decker, 2007; Enskär & von Essen, 2007; Goodall, King, Ewing, Smith, & Kenny, 2012; Miedema et al., 2007; Zebrack, 2011; Zebrack et al., 2006). Results from this study not only provide support for these previous findings, but also provide support that the relationship between the patient and caregiver is associated with the patient's ability to effectively manage his or her adjustment to the cancer treatment.

The findings regarding the association between coping strategies, relationship satisfaction and distress were not as strong for the unmatched sample of caregivers. Among caregivers, caregiver burden was the only significant predictor and was associated with higher PPL score. Researchers have previously reported that caregivers' distress may be related to caregiving burden (e.g., Bevans & Sternberg, 2012; Fujinami et al., 2014). Caregivers may struggle to manage their own symptoms because of their caregiving responsibilities. Furthermore, previous researchers have reported that perceived caregiving burden was not directly related to the number of caregiving hours but was rather based on the subjective experience of being a caregiver and the availability of additional support (Sternberg et al., 2010). Caregivers of AYAs, such as parents or new spouses, may be struggling to make sense of what it means to be a caregiver to a young adult.

AYA are confronted with the challenges of treatment while also attending to normative developmental tasks associated with emerging adulthood (Arnett, 2000, 2003) such as exploring education and career opportunities, gaining independence from their families of origin, and building new relationships, including with partners, friends and other parts of their support system. Similarly, caregivers such as parents or partners may not necessarily view cancer as a normal aspect of this developmental phase and may be struggling in making sense of what it means for a young adult to have cancer and then what it means for them to be a caregiver of a young adult with cancer. Helping caregivers make sense of their experience while maintaining engagement with the patient may be beneficial to both the patient and the caregivers.

Approximately one-third of the unmatched caregiver sample were parents. Parents of young adults with cancer parents may not know how to manage the changes in the relationship with their child. The normative developmental tasks, as discussed through the theory of emerging

adulthood, include the transition from dependence on the family of origin to independence (Arnett, 2003). Some young adults, who were independent prior to being diagnosed with cancer, may become dependent on their parents during cancer treatment. These parents may not know how to manage the changes in their relationships while also managing their role as a caregiver (Barling, Stevens, & Davis, 2013) and adjusting to knowing that their child has cancer. These parents may also be balancing other responsibilities such as work, caring for aging parents, and possibly still providing care for other children. For those patients who are married or in committed relationships, they become dependent on a partner in a way that the couple may not be ready to manage (Stenberg et al., 2010). This change from independence to dependence may be an additional source of stress during a time already known for being stressful. Additional efforts are needed to understand what other systems of support are available to caregivers of young adults with cancer in order to provide caregivers the necessary support to manage the magnitude of their potential responsibilities and their role as a caregiver.

The interconnected nature of distress and coping was also assessed using actor-partner interdependent models (APIM) with a sample of 19 matched patients and caregivers that included a large portion of breast cancer and spousal caregivers. Three APIMs provided preliminary support that the experience of acute distress and coping is indeed interrelated among young adults with cancer and their caregivers. Increased use of engagement coping strategies among caregivers was significant in predicting lower DT and PPL scores among patients. While many AYA patients desire to maintain a sense of normalcy as they go through cancer treatment (Miedema et al., 2007), AYA patients value talking to family and friends about cancer and non-cancer related issues (Hilton, Emslie, Hunt, Chapple, & Ziebland, 2009; Miedema et al., 2007; Trevino, Fasciano, Block, & Prigerson, 2012). Based on the findings from chapter five, AYA

patients also seem to benefit from caregivers who are able to utilize in engagement coping strategies such as problem solving, expressing emotion, social contact, and cognitive restructuring. Having someone to talk to may be even more important to AYAs' overall psychological well-being than receiving tangible support (Trevino et al., 2012).

Similarly, findings from the APIM analysis also suggest that caregivers' distress is influenced by patients' use of coping strategies. Greater use of disengagement coping strategies among patients was significant in predicting lower PPL scores among caregivers. Previously researchers reported that negative coping strategies, such as disengagement, were associated with increased dyadic distress (Badr, Carmack, Kashy, Cristofanilli, & Revenson, 2010; Feldman & Broussard, 2006; Lafaye et al., 2014; Rottmann et al., 2015); however, findings from this study suggest that this may not apply to AYAs and their caregiver. This may be associated with caregivers' confidence in their role, which has been previously reported to be associated with the decreased severity of the patients' symptoms, availability of additional support, and the quality of the patient-caregiver relationship (Barling et al., 2013). If patients are using disengagement strategies such as problem avoidance, wishful thinking, and social withdrawal, then caregivers may not be aware of the severity of the patient's symptoms or assuming that the patient is adjusting better than he or she really is. If the caregiver thinks that the patient is doing well, then it is plausible that the caregiver may feel less distressed.

Despite the limited generalizability of the findings from the APIM analysis, overall the findings from the study in chapter five support the application of STM (Bodenmann, 1995, 2005) for examining the interconnected nature of distress and coping among young adults with cancer and their caregivers. Similar to older patients and their caregivers (e.g., Gregorio et al., 2012; Kim & Given, 2008; Segrin, Badger, Dorros, Meek, & Lopez, 2007), coping and distress appears

to be interrelated among AYA oncology patients and their caregivers. Patients' distress was associated with higher patient-caregiver relationship satisfaction, while caregivers' distress was associated with higher levels of caregiver burden. Furthermore, findings from the APIM analysis that patients' distress was reduced by greater use of engagement coping strategies among their caregivers. In contrast, caregivers' distress is reduced by greater use of disengagement strategies by patients. AYA patients have previously reported that talking with their family and friends about cancer and non-cancer related issues is important to their well being (Hilton et al., 2009; Miedema et al., 2007; Trevino et al., 2012), which supports the need for caregivers to be able to be present for patients' as they make sense of their experience of having cancer. As caregivers are important to patients' distress, caregivers need additional support in managing their caregiving responsibilities and their emotional well being, so they maintain a high level of engagement in their relationship with the patient. These findings have not previously been reported in the literature and need to be further evaluated to determine how generalizable it is to the entire AYA patient-caregiver dyad.

The results of the two articles included in this dissertation provide evidence that the experience of cancer among AYAs is influenced by sociodemographic variables (chapter 2) and relational dynamics (chapter 5). Findings from these two articles suggest a need to understand more about the systemic influences on the experience of cancer among young adults. Given the findings of these research articles, several implications for Medical Family Therapy (MedFT) clinicians, researchers, and policy makers are discussed.

Clinical Implications

The findings in article two (chapter five) provide preliminary evidence for the dyadic nature of distress and coping among young adults with cancer and their caregivers, particularly

the interrelatedness of engagement and disengagement coping strategies on patients' and caregivers' acute and overall distress. As well, the findings suggest that patients rely on a variety of caregivers for support, including parents, partners, friends, spouses, and others. AYA patients have previously reported that parents, spouses, and friends are an important source of support for coping and adjusting to the illness experience (Woodgate, 2006). This information is particularly useful to clinicians, including MedFTs, who are providing therapeutic support to AYA patients during cancer treatment. As a part of the biomedical, psychological, social, and spiritual assessment common to the practice of MedFT (Hodgson, Lamson, Mendenhall, & Crane, 2014), clinicians should seek out who the patient identifies as their primary caregiver and assess the quality of the relationship. Findings from article two suggest that AYAs rely on a variety of caregiver types, higher relationship satisfaction is associated with lower levels of acute and overall patient distress, and that distress and coping are interrelated among patients and their caregivers. This provides the clinician an opportunity to help the patient and caregiver improve their relationship or help the dyad increase their engagement with additional sources of support. Clinicians may even want to consider adding the Relationship Assessment Scale (Hendrick, 1988) to their inventory of measures as it is short and can be used with a variety of dyads (e.g., friends, parent-child, spouses).

Second, clinicians should make efforts to incorporate caregivers into the treatment plan and therapy sessions as often as possible. Patients reported that their relationships with their caregivers were the most important relationships when faced with cancer (Coyne, Wollin, & Creedy, 2012; Hagedoorn, Buunk, Kuijer, Wobbes, & Sanderman, 2000; Zebrack, Mills, & Weitzman, 2007). Findings from article two suggest that caregivers' distress and coping strategies are closely connected to patients' distress and coping strategies and thus provide

another layer through which clinicians can intervene. Caregivers have previously reported multiple decrements in physical and psychosocial health (Girgis et al., 2013; Northouse et al., 2012; Stenberg et al., 2010). Caregivers reported symptoms including greater frequency of headaches, fatigue, sleep troubles, back, neck and shoulder problems, digestion problems and stress-related illnesses (Girgis et al., 2013).

Parental caregivers of AYAs previously reported experiencing distress, isolation, and decrements in their own physical and emotional health (Barling et al., 2013; Grinyer, 2006). These parents also discussed the challenges of providing care, while managing the household and other children (Barling et al., 2013; Grinyer, 2006). This all points to appreciating that some groups of caregivers of AYA patients may be more distressed than others. Caregiver distress may be related to type of care provided, the patient's symptoms, physical health and distress levels, and caregiving burden (Applebaum & Breitbart, 2013; Hodges, Humphris, & Macfarlane, 2005; Northouse et al., 2012; Stenberg, Cvancarova, Ekstedt, Olsson, & Ruland, 2014). Clinicians who are able to help caregivers manage their distress and caregiver burden may indirectly increase patients' abilities to manage their distress, as supported by STM (Bodenmann, 1995, 2005). Despite that some caregivers may prefer to disengage from the patients, findings from this study suggest that caregivers' engagement is important to reducing patients' distress. Therefore, clinicians who are able to empower caregivers to use engagement coping strategies, such as problem-solving, cognitive restructuring, expressing emotions, and increasing social contacts, may be able to help caregivers, as well as indirectly reduce patients' distress. Helping caregivers accept that talking about cancer and non-cancer related issues is beneficial to young adults with cancer may help reduce their use of disengagement strategies.

Beyond working together with patients and their caregivers, clinicians should also build

their awareness of some of the disparities and systemic issues that some AYAs face as identified through the systematic review (chapter two). While additional research is necessary to truly understand the extent of the disparities faced by AYAs, findings from the systemic review suggest that some AYAs face decrements in incidence and mortality, access to care, and differing levels of unmet supportive care needs. With this information, clinicians can work with the healthcare system to develop steps for addressing these disparities through their clinical and larger systems work (e.g., advocacy, community engagement, policy development). For example, clinicians may want to participate in outreach work to develop stronger relationships with the communities in their regions who are experiencing disparities at any stage in the cancer journey.

Research Implications

As previously stated, relational and systemic research is needed with AYA oncology patients in order to truly capture their experiences of being diagnosed with and undergoing treatment for cancer which is necessary for developing interventions and programs that meet the complexity of their biopsychosocial and spiritual needs (Engel, 1977, 1980; Wright, Watson, & Bell, 1996). First, more exploratory research is needed about how larger systems issues influence AYA patients' experience with cancer, as discussed in chapter two. There are several ways that this can be approached. One way is to expand registries to capture more information about how sociodemographic variables are associated with incidence and mortality. In expanding registries, it is important that sufficient resources are put into place to ensure that information is captured in its entirety for all patients. It would also be beneficial for researchers to consistently examine the interactions between sociodemographic variables in order to understand patients as more than one sociodemographic variable. Intersectionality theory (Crenshaw, 1989, 1991, 1995), as

discussed in the first article (chapter two), provides a valuable framework for analyzing the interaction of multiple sociodemographic variables in understanding healthcare disparities.

Another approach is to increase the use of electronic health record data to understand how AYA patients are and are not accessing the healthcare system, what preventative measures are being recommended, what screening tests are being performed, and how patients navigate through the system prior to beginning treatment. This information would be valuable in helping understand some of the access to care issues that some AYAs are facing. Identifying how access to care is limited or challenged is incredibly useful to creating targeted interventions and quality improvement initiatives.

Based on the findings from chapter five, additional research is needed to understand the relational context of patients' experience with cancer through dyadic and social networks research designs. A large portion of research about AYA patients' experience of cancer has been limited to data collected from only the patient (e.g., Patterson, McDonald, Zebrack, & Medlow, 2015; Trevino et al., 2012; Yanez, Garcia, Victorson, & Salsman, 2013) and very few studies have incorporated patients' caregivers or other members of patients' support systems (Juth, Silver, & Sender, 2015). Patients do not go through cancer in isolation as they are in constant interaction with their support systems (e.g., Bellizzi et al., 2012; Carpentier & Fortenberry, 2010; Decker, 2007; Enskär & von Essen, 2007; Goodall, King, Ewing, Smith, & Kenny, 2012; Miedema et al., 2007; Zebrack, 2011; Zebrack et al., 2006), thus research from a relational lens may provide valuable insight into the complexity of patients' lived experiences. Family and friends are important to AYA patients' adjustment and ability to cope with cancer (Kwak et al., 2013; Kyngas et al., 2001; Woodgate, 2006). However, if these family and friends are themselves distressed and struggling with positive coping strategies, their ability to help the

patient may be limited and they may experience higher PPL scores. As researchers expand their use of dyadic and social network research designs (e.g., Kenny, Kashy, & Cook, 2006; Scott, 2012), specific implications regarding the recruitment of dyads are provided to help researchers consider the most effective ways of recruited dyads and other parts of the patients' social support system.

The need for more dyadic and social networks research designs raises the issue of recruitment of such study samples. One of the challenges faced in the execution of the study design utilized in chapter five was the recruitment of patient-caregiver dyads through social media (i.e., Facebook and Twitter). The research team posted announcements about the study to 401 Facebook pages and 102 Twitter accounts up to 12 times between July 2015 and February 2016. It is difficult to capture exactly how many potential participants read the study announcement because depending on the Facebook pages' settings, the announcement was either posted directly to the main wall or to a visitor wall. Posts on the visitor wall do not appear in individuals' news feeds and cannot be seen from a mobile device. As well, some Facebook groups also notified the first author that they had shared the study announcement on a private page. The variability in how Facebook and Twitter was used to reach out to potential participants makes it difficult to determine exactly how many people saw the study announcement.

While this approach led to a sufficient sample of patients, using internet-based recruitment strategies were not as successful in capturing a large sample of dyads or a racially or ethnically diverse sample. When participants were completing the study survey they were asked to enter the email address of their dyad partner so that their dyad partner could be invited to participate in the study. The use of the internet-based recruitment approach used in this study may have actually identified two different communities of caregivers, those who are engaged

with the patient (dyadic sample) and those who are not as emotionally close with their patient (unmatched sample). It is unclear from this recruitment approach whether the patient invited the caregiver to participate or vice versa, but there is likely something about their relationship that resulted in both members of the dyad participating. Future researchers should consider this as they consider the most efficient and effective approaches to enrollment of patients and caregivers.

As previously discussed, this study identified two unique samples of caregivers; those who participated in the dyadic portion and those who participated without their matched patient. Caregivers in the unmatched sample might actually be quite different from those in the dyadic sample. Caregivers who are experiencing high distress and may not have a solid relationship with their patient, or may not want to burden them, and may be more likely to lean on web-based supports to help manage their distress, versus the patient. This may explain why the unmatched caregivers were more distressed than the caregivers in the dyadic sample. It is also plausible that caregivers in the matched sample may have additional sources of support beyond the patient. Future research should evaluate which types of supports caregivers use and consider how the use of those supports (e.g., forums, online support groups, therapy, social contact, relationships, work) is associated with their relationship satisfaction, coping strategies, and distress levels. If the caregivers of AYAs who do not have a solid relationship with their patients are truly more distressed than those caregivers who are engaged with their patient, this would have serious implications for the clinical care of this caregiver community.

The answer to these questions is valuable for further understanding how relational dynamics influence patients' experience with cancer. It is possible that those that chose to not enter the email address of their dyad partner may have a different type of relationship with their

caregiver as compared to those who entered the email address of their caregiver. Findings in article two suggests that there is no difference in how satisfied patients are with their relationship between those who participated in the dyadic portion, as compared to those who participated independent of their caregiver. Similarly, there was no difference in how satisfied caregivers are with their relationship among those who participated in the dyadic portion as compared to those who participated independent of the patient. Future researchers may want to assess additional aspects of the patient-caregiver dynamic, such as perceived burden, length of the relationship, expectations of the relationship, and additional quality measures.

The lack of racial diversity in the study sample for article two suggests that web-based recruitment was not successful in reaching a racially diverse patient and caregiver population despite web-based recruitment being the most successful method of recruitment for young adults into survey studies (Rabin, Horowitz, & Marcus, 2013). Lack of racial and ethnic diversity has been documented in multiple studies with AYA patients where a web-based internet approach was employed (e.g., Salsman et al., 2014; Yanez et al., 2013; B. J. Zebrack et al., 2007; B. Zebrack, 2008, 2009). Studies that have been able to capture the greatest racial diversity among AYA patients have utilized community based recruitment strategies (e.g., Casillas et al., 2010; Zebrack et al., 2013). Cognizant of the potential for a lack of racial or ethnic diversity in the study sample discussed in article two, the research team posted to multiple racial or ethnically specific Facebook groups (e.g., Mi ACS: American Cancer Society-Latino, Young Sisters Initiative). Supplementing web-based recruitment with local community collaboration may have increased the racial and ethnic diversity of the sample and should be considered for future studies. Given the additional disparities faced by some AYA patients, as identified in chapter

two, including a racially diverse sample is important to building a knowledge base for all patients rather than for one group of patients.

Policy Implications

With the increase of AYA-specific programs opening nationally (Reed et al., 2014), there has been an increased push towards providing developmentally appropriate care for patients. AYA oncology patients are recognized for having complex psychosocial issues and needs (e.g., Carey et al., 2012; Dyson et al., 2012; Zebrack et al., 2007). They are confronted with the challenges of treatment while also attending to normative developmental tasks associated with emerging adulthood (Arnett, 2000, 2003) such as exploring education and career opportunities, gaining independence from their families of origin, and building new relationships, including with partners, friends and other parts of their support system. Policy changes are needed to ensure that all AYA patients are receiving accessible and high quality care, including from medical providers that have an understanding of the uniqueness of this patient population and from an integrated care team that can support their unique individual, relational, and systemic issues.

Chapter two of this dissertation identified some of the sociodemographic variables associated with disparities in incidence, mortality, access to care, and unmet health and supportive care needs that AYA oncology face. To be able to address these disparities, additional training is needed about AYA-specific biopsychosocial issues. Hayes-Lattin, Mathews-Bradshaw, and Siegel (2010) released a position paper outlining the essential elements that are needed for training of healthcare professionals who work with AYA oncology patients, including the need to attend to health disparities and relational issues. More policies are necessary in order to put these recommendations into practice. Additional education and training

about AYAs through a relational and systemic lens must be added to oncology training, nursing, and behavioral health programs in order to prepare healthcare providers to work with this patient population. As well, training programs may want to consider developing fellowships or certificates in AYA Oncology across disciplines. Subspecialty training for oncologists is already being explored (Hayes-Lattin et al., 2010).

As more recognition is being given to the inter- and intrapersonal experience of cancer for AYAs, cancer settings should consider whether a family-centered approach to AYA oncology care is the best fit for this patient population. Findings from chapter five suggest that distress and coping are interrelated among patients and their caregivers. Adding an integrated Medical Family Therapist to an oncology team would bring the system closer to operating from a family-centered approach. Medical Family Therapists help to increase the healthcare system's attention to relational issues, while also working direct with patients and their families during brief encounters or traditional therapy sessions to manage relational and systemic issues (Hodgson et al., 2014). AYA programs should also consider how to ensure that support services are equally accessible to patients, as well as family members and caregivers.

Financial changes are a necessity in order to truly shift to a relational or systemic clinical care approach. In our current fee-for-service payment model, providers are reimbursed based on the type of service that he or she provides the patient which means they are reimbursed based on the quantity rather than the quality of the care provided to the patient (Porter & Teisberg, 2006). This results in a heavy focus on providing a maximum number of billable services for the insurance beneficiary per each visit. Moving towards a value-based payment model would give oncology providers more flexibility to attend to relational and systemic issues since they are no longer focused on providing billable services. Multiple systems across the

United States are currently piloting value-based payment models and have reported positive preliminary outcomes including lower cost of care and better health outcomes (e.g., Burswell, 2015; Damberg et al., 2014; Song et al., 2014). Given the systemic and relational issues identified through chapters two and five, respectively, considering alternative payment models are necessary in order to meet the unique biopsychosocial needs of this patient population.

Conclusion

The articles in this dissertation provide new and valuable insight into the larger systems issues that AYA oncology patients face, as well as how relational dynamics influence patients' distress and coping strategies. Through this research, the need for a more systemic and relational approach to research and clinical care for AYA oncology patients is recognized. Utilizing a more systemic and relational approach will provide researchers and clinicians a better understanding of the lived experience of AYAs with cancer and will help AYA program administrators and clinicians develop targeted interventions aimed at meeting the unique psychosocial needs of this patient and caregiver population. Several recommendations were made in this chapter for clinicians and researchers based on the findings of this dissertation.

As research findings, such as those presented in chapters two and five, are used to build the knowledge base about AYA oncology patients within their social contexts, several steps need to be taken. First, clinicians must expand their lens from an individual lens to a relational lens where caregivers and other members of the AYA's support system are incorporated into their clinical care. The patient-caregiver system should be seen as the unit of treatment as the findings from this study suggest their ability to survive the journey is more interdependent than independent, as previously thought. Second, clinicians must attend to the distress and coping of the AYA's support system, given the interrelated nature of distress and coping identified through

this dissertation. Finally, researchers need to utilize dyadic and social network research designs in order to continue to build the knowledge base.

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APPENDIX A: INSTITUTIONAL REVIEW BOARD DOCUMENTS

1. INSTITUTIONAL REVIEW BOARD (IRB) PERMISSION



EAST CAROLINA UNIVERSITY
University & Medical Center Institutional Review Board Office
4N-70 Brody Medical Sciences Building · Mail Stop 682
600 Moye Boulevard · Greenville, NC 27834
Office 252-744-2914 · Fax 252-744-2284 · www.ecu.edu/irb

Notification of Exempt Certification

From: Social/Behavioral IRB
To: [Irina Kolobova](#)
CC: [Jennifer Hodgson](#)
Date: 7/6/2015
Re: [UMCIRB 15-001047](#)
Distress among AYA Oncology Patients and their Caregivers

I am pleased to inform you that your research submission has been certified as exempt on 7/3/2015 . This study is eligible for Exempt Certification under category # 2.

It is your responsibility to ensure that this research is conducted in the manner reported in your application and/or protocol, as well as being consistent with the ethical principles of the Belmont Report and your profession.

This research study does not require any additional interaction with the UMCIRB unless there are proposed changes to this study. Any change, prior to implementing that change, must be submitted to the UMCIRB for review and approval. The UMCIRB will determine if the change impacts the eligibility of the research for exempt status. If more substantive review is required, you will be notified within five business days.

The UMCIRB office will hold your exemption application for a period of five years from the date of this letter. If you wish to continue this protocol beyond this period, you will need to submit an Exemption Certification request at least 30 days before the end of the five year period.

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

2. Inclusion and Exclusion Checklists

Inclusion and Exclusion Checklist for Patients

Please check YES or NO for each of the following questions. These questions will help us to ensure that you are eligible for this study:

1. Are you currently between the ages of 18 and 39?
2. Have you been diagnosed with a leukemia, lymphoma or sarcoma cancer within the past two years
3. Prior to this most recent diagnosis, have you been previously diagnosed with cancer?
4. Are you currently receiving treatment for a leukemia, lymphoma or sarcoma cancer?
5. Have you completed treatment for a leukemia, lymphoma or sarcoma cancer within the previous year?
6. Do you currently reside in the United States?

Inclusion and Exclusion Checklist for Caregivers

Please check YES or NO for each of the following questions. These questions will help us to ensure that you are eligible for this study:

1. Are you currently at least 18 years old?
2. Are you currently or have been within the past year a caregiver to a young adult diagnosed with cancer while the individual underwent treatment for a leukemia, lymphoma or sarcoma cancer?
3. Do you currently reside in the United States?
4. Have you been diagnosed with cancer in the past two years?

3. Study Consent Document (Exempt Survey Research)

You are being invited to participate in a **research** study titled “Distress and Coping among AYA Oncology Patients and their Caregivers” being conducted by Irina Kolobova, MA, CCRP, a Medical Family Therapy doctoral student at East Carolina University in the Child Development and Family Relations department. The goal is to survey 200 individuals in the United States. The survey will take approximately 20-35 minutes to complete. It is hoped that this information will assist us to better understand how young adult cancer patients and their caregivers cope with distress when dealing with cancer. From this study we are hoping to help healthcare teams find additional ways of being supportive to patients and their caregivers. The survey is anonymous, so please do not write your name. Your participation in the research is **voluntary**. You may choose not to answer any or all questions, and you may stop at any time. There is **no penalty for not taking part** in this research study. Please call Irina Kolobova, MA at 252-737-1415 or Jennifer Hodgson, PhD 252-737-1349 for any research related questions or the Office of Research Integrity & Compliance (ORIC) at 252-744-2914 for questions about your rights as a research participant.

4. HIPAA Exemption Email

Friday, May 22, 2015 at 3:51:45 PM Eastern Daylight Time

Subject: RE: Confirm a question about HIPAA and PHI
Date: Friday, March 20, 2015 at 8:27:00 AM Eastern Daylight Time
From: Matos, Sandy
To: Sparrow, Suzanne
CC: Kolobova, Irina

HIPAA regs would not apply unless she was recruiting with a Healthcare Component or was entering the medical record of the participant. General recruitment from the public and gathering data from the participant does not make HIPAA apply.

Sandy Matos
HIPAA Research Analyst
Office of Research Integrity and Compliance
4N-70B Brody School of Medicine
252-744-0409
matoss@ecu.edu

From: Sparrow, Suzanne
Sent: Friday, March 20, 2015 8:22 AM
To: Matos, Sandy
Cc: Kolobova, Irina
Subject: FW: Confirm a question about HIPAA and PHI

Sandy,
This is the study I discussed with you last week where Irina (student in the MFT program in CDFR, see below) is recruiting from places like facebook pages, online forums, etc (not from any medical record/clinic) in order to get people to complete a survey which will include identifiers. Since this department is not listed as a Health Care Component and no medical records are being accessed, HIPAA rules would not apply, correct?

I have copied Irina on this email in case she needs to add anything or there are any questions, etc.

Thanks,
Suzanne

5. Study Flyer

YOUNG ADULTS WITH CANCER & THEIR CAREGIVERS ARE NEEDED FOR A RESEARCH STUDY



Researchers at East Carolina University are seeking young adult cancer patients, between the ages of 18 and 39, and their caregivers to participate in an online survey study. The purpose of this study research is to learn more about patients and their caregiver experience distress and coping. Our hope is that it will provide information about the types of services that may be helpful.

WHO IS ELIGIBLE?

Patients:

Aged 18 – 39
Diagnosed with a leukemia,
lymphoma or sarcoma cancer
in the past two years

Caregivers:

At least 18 years of age
Was/is a primary caregiver for a
young adult with a leukemia,
lymphoma or sarcoma center

WHAT WILL BE ASKED OF YOU?

Complete an online survey that will take 20-30 minutes

COMPENSATION?

Entered into a raffle for one of twenty \$10 gift cards

READY TO ENROLL? Follow this link to the survey: [STUDY LINK](#)



If you have questions, please contact
Irina Kolobova, MA at 252-737-1415 or
email Kolobovai13@students.ecu.edu

APPENDIX B: STUDY MEASURES

*Measures are featured in the order that participants would complete them after they complete the consent form

1. Demographic Surveys

Demographic Survey for Patients

Can you please tell us about you by answering the following questions?

1. Age at diagnosis _____
2. Current age _____
3. Gender: M F MTF FTM Gender Fluid other: _____
4. Race: White African-American/Black Asian/Pacific Islander American Indian/Alaskan Native Bi-racial Multi-racial Other: _____
5. Ethnicity: Hispanic non-Hispanic
6. Primary language spoken at home: _____
7. Current relationship status: single dating cohabitating married divorce widowed other: _____
8. Sexual orientation _____
9. Current living arrangement:
 - Living alone
 - Living with a partner or spouse
 - Living with roommates or friends
 - Living with parents
 - Living with spouse and children
 - _____
10. Highest level of education completed: HS AA/AS some college BA/BS MA/MS professional degree (MD, DDS) JD PhD

11. Annual Household Income: \$0-10,000 \$10,001 – \$20,000 \$20,001 - \$30,000 \$30,001 - \$40,000
\$40,001 - \$50,000 \$50,001 - \$60,000 \$60,001 - \$70,000 \$70,001 - \$80,000 \$80,001 - \$90,000

12. What type of cancer do you have: _____

a. Diagnosis (provide as much information as you know) _____

13. Date of diagnosis: _____

14. Were you treated in an adult setting or a pediatric setting? Adult Pediatric

15. Distance to primary treatment center: 0-10 11-20 21-30 31-40 41-50 51+

16. Select all of the treatments that you received:

Surgery

Chemotherapy

Radiation

Bone Marrow or Stem Cell Transplant

Hormone Replacement Therapy

17. Date of first treatment:

18. Current treatment status: active follow up

19. Relationship to the individual that you identify as your primary caregiver while you have had cancer: parent child friend partner spouse other: _____

The following questions are important for the researchers to be able to connect your survey results with your caregiver's survey results.

- The first two letter of your first name: _____
- The first two letters of your last name: _____
- The first two letters of your caregiver's first name: _____
- The first two letters of your caregiver's last name: _____
- Your caregiver's current age: _____

Demographic Survey for Caregivers

Can you please tell us about you by answering the following questions?

1. Your current age: _____
2. Gender: M F MTF FTM Gender Fluid other: _____
3. Race: White African-American/Black Asian/Pacific Islander American Indian/Alaskan Native Bi-racial Multi-racial Other: _____
4. Ethnicity: Hispanic non-Hispanic
5. Primary language spoken at home: _____
6. Current relationship status:
 - i. single dating cohabitating married divorce widowed other: _____
7. Sexual orientation _____
8. Current living arrangement:
 - Living alone
 - Living with a partner or spouse
 - Living with roommates or friends
 - Living with parents
 - Living with spouse and children, including number of children: _____
 - _____
9. Highest level of education completed: HS AA/AS some college BA/BS MA/MS professional degree (MD, DDS) JD PhD
10. Annual Household Income: \$0-10,000 \$10,001 – \$20,000 \$20,001 - \$30,000 \$30,001 - \$40,000 \$40,001 - \$50,000 \$50,001 - \$60,000 \$60,001 - \$70,000 \$70,001 - \$80,000 \$80,001 - \$90,000

The following questions are about the young adult that you have been taking care of:

20. Age at diagnosis of the patient that you are caring for: _____
21. Current Age at diagnosis of the patient that you are caring for: _____

22. Patient's gender: M F MTF FTM Gender Fluid other: _____

23. Which of these cancers does/did the patient:

Lymphoma Leukemia Sarcoma

a. Diagnosis (provide as much information as you know) _____

24. Date of diagnosis: _____

25. Was the patient treated in an adult setting or a pediatric setting? Adult Pediatric

26. Distance to primary treatment center: 0-10 11-20 21-30 31-40 41-50 51+

27. Select all of the treatments that the patient received:

Surgery Chemotherapy Radiation

Bone Marrow or Stem Cell Transplant Hormone Replacement Therapy

28. Date of first treatment: _____

29. Patient's current treatment status: active follow up

30. Relationship to the individual that you have been providing care to:

parent child friend partner spouse other: _____

The following questions are important for the researchers to be able to connect your survey results with your caregiver's survey results.

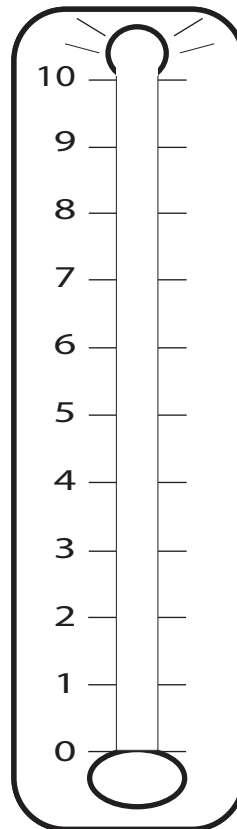
- The first two letter of your first name: _____
- The first two letters of your last name: _____
- The first two letters of the patient' (you are caring for) first name: _____
- The first two letters of the patient' (you are caring for) last name: _____

2. Distress Thermometer and Patient Problem List

SCREENING TOOLS FOR MEASURING DISTRESS

Instructions: First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

Extreme distress



No distress

Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

YES NO Practical Problems

- Child care
- Housing
- Insurance/financial
- Transportation
- Work/school
- Treatment decisions

Family Problems

- Dealing with children
- Dealing with partner
- Ability to have children
- Family health issues

Emotional Problems

- Depression
- Fears
- Nervousness
- Sadness
- Worry
- Loss of interest in usual activities

- Spiritual/religious concerns**

YES NO Physical Problems

- Appearance
- Bathing/dressing
- Breathing
- Changes in urination
- Constipation
- Diarrhea
- Eating
- Fatigue
- Feeling Swollen
- Fevers
- Getting around
- Indigestion
- Memory/concentration
- Mouth sores
- Nausea
- Nose dry/congested
- Pain
- Sexual
- Skin dry/itchy
- Sleep
- Substance abuse
- Tingling in hands/feet

Other Problems: _____

3. Perceived Social Stress Scale

PSS

INSTRUCTIONS:

The questions in this scale ask you about your feelings and thoughts during **THE LAST MONTH**. In each case, please indicate your response by placing an “X” over the circle representing **HOW OFTEN** you felt or thought a certain way.

	Never 0	Almost Never 1	Sometimes 2	Fairly Often 3	Very Often 4
1. In the last month, how often have you been upset because of something that happened unexpectedly?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. In the last month, how often have you felt that you were unable to control the important things in your life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. In the last month, how often have you felt nervous and “stressed”?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. In the last month, how often have you felt confident about your ability to handle your personal problems?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. In the last month, how often have you felt that things were going your way?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. In the last month, how often have you found that you could not cope with all the things that you had to do?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. In the last month, how often have you been able to control irritations in your life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. In the last month, how often have you felt that you were on top of things?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. In the last month, how often have you been angered because of things that were outside your control?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

4. Relationship Assessment Scale

For each question, please circle one number that best represents your response regarding how you feel about your relationship with your caregiver or with the individual you are caring for

	Low				High
1. How well does your caregiver/individual you are caring for meet your needs?	1	2	3	4	5
2. In general, how satisfied are you with your relationship?	1	2	3	4	5
3. How good is your relationship compared to most?	1	2	3	4	5
4. How often do you wish you hadn't gotten into this relationship?	1	2	3	4	5
5. To what extent has your relationship met your original expectations?	1	2	3	4	5
6. How much do you love your caregiver/individual you are caring for?	1	2	3	4	5
7. How many problems are there in your relationship?	1	2	3	4	5

5. Coping Strategies Inventory

Take a few moments to think about your experience with cancer as a patient or if you are a caregiver, your experience being a caregiver to a young adult with cancer. As you read through the following items please answer them based on how you handled your event.

Please read each item below and circle the number that best represents the extent to which you used it in handling this event.

	Not all	A Little	Some what	Much	Very Much
1. I worked on solving the problems in the situation.	1	2	3	4	5
2. I looked for the silver lining, so to speak; I tried to look on the bright side of things.	1	2	3	4	5
3. I let out my feelings to reduce the stress.	1	2	3	4	5
4. I found somebody who was a good listener.	1	2	3	4	5
5. I went along as if nothing were happening.	1	2	3	4	5
6. I hoped a miracle would happen.	1	2	3	4	5
7. I realized that I was personally responsible for my difficulties and really lectured myself	1	2	3	4	5
8. I spent more time alone.	1	2	3	4	5
9. I made a plan of action and followed it.	1	2	3	4	5
10. I looked at things in a different light and tried to make the best of what was available.	1	2	3	4	5
11. I let my feelings out somehow.	1	2	3	4	5
12. I talked to someone about how I was feeling.	1	2	3	4	5
13. I tried to forget the whole thing.	1	2	3	4	5
14. I wished that the situation would go away or somehow be over with.	1	2	3	4	5
15. I blamed myself.	1	2	3	4	5
16. I avoided my family and friends.	1	2	3	4	5
17. I tackled the problem head on.	1	2	3	4	5
18. I asked myself what was really important, and discovered that things weren't so bad after all.	1	2	3	4	5
19. I let my emotions out.	1	2	3	4	5
20. I talked to someone that I was very close to.	1	2	3	4	5
21. I didn't let it get to me; I refused to think about it too much.	1	2	3	4	5
22. I wished that the situation had never started.	1	2	3	4	5
23. I criticized myself for what happened.	1	2	3	4	5

24. I avoided being with people.	1	2	3	4	5
25. I knew what had to be done, so I doubled my efforts and tried harder to make things work.	1	2	3	4	5
26. I convinced myself that things aren't quite as bad as they seem.	1	2	3	4	5
27. I got in touch with my feelings and just let them go.	1	2	3	4	5
28. I asked a friend or relative I respect for advice.	1	2	3	4	5
29. I avoided thinking or doing anything about the situation.	1	2	3	4	5
30. I hoped that if I waited long enough, things would turn out OK.	1	2	3	4	5
31. Since what happened was my fault I really chewed myself out.	1	2	3	4	5
32. I spent some time by myself.	1	2	3	4	5

6. Zarit Burden Inventory (for caregivers only)

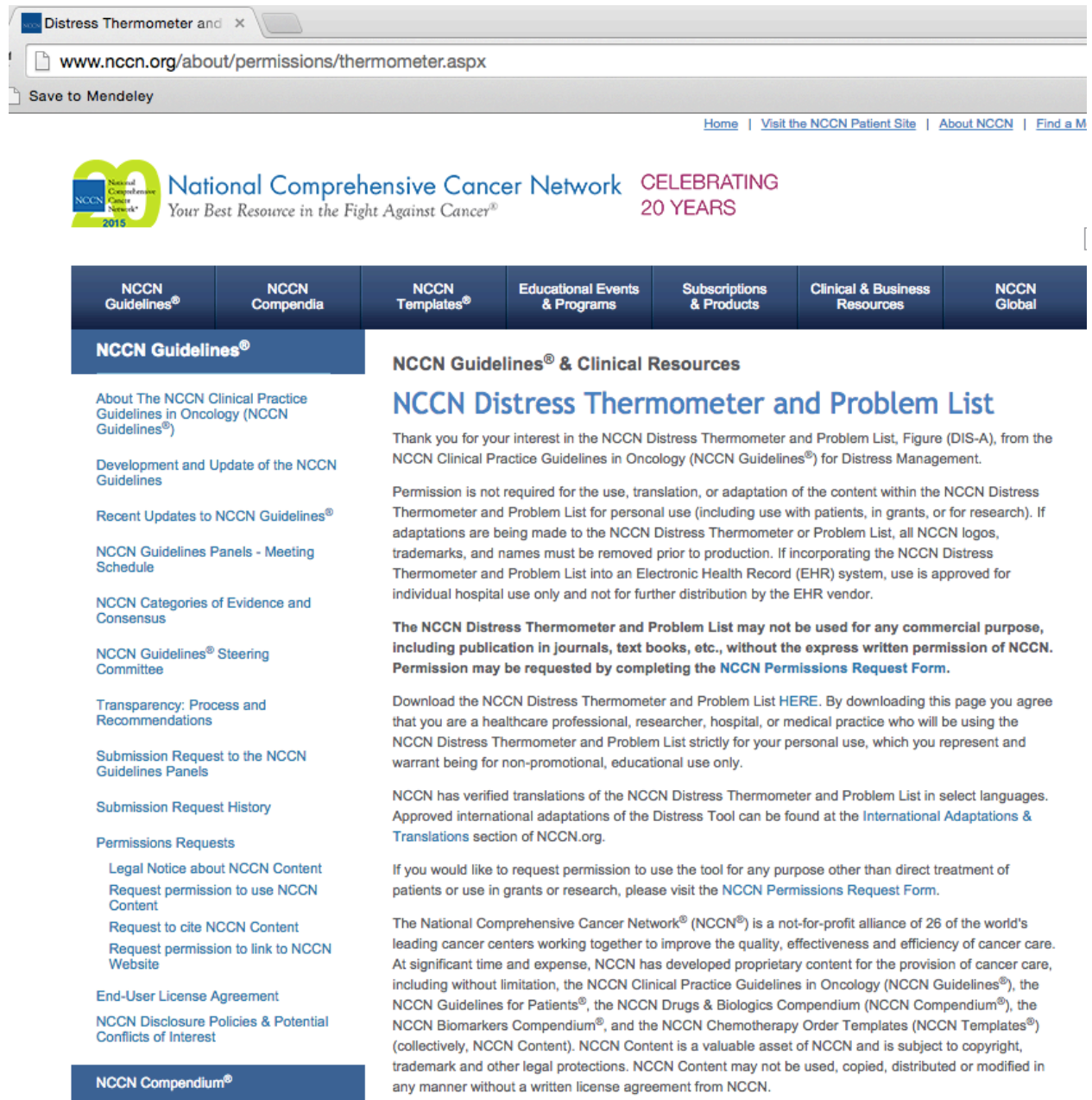
Please circle the response the best describes how you feel.

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
1. Do you feel that your relative asks for more help than he/she needs?	0	1	2	3	4
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4. Do you feel embarrassed over your relative's behaviour?	0	1	2	3	4
5. Do you feel angry when you are around your relative?	0	1	2	3	4
6. Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?	0	1	2	3	4
7. Are you afraid what the future holds for your relative?	0	1	2	3	4
8. Do you feel your relative is dependent on you?	0	1	2	3	4
9. Do you feel strained when you are around your relative?	0	1	2	3	4
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
11. Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
13. Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4

14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4
15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0	1	2	3	4
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4
18. Do you wish you could leave the care of your relative to someone else?	0	1	2	3	4
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20. Do you feel you should be doing more for your relative?	0	1	2	3	4
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4

APPENDIX C: PERMISSIONS TO USE MEASURES

1. Distress Thermometer and Patient Problem List




The screenshot shows a web browser window with the URL www.nccn.org/about/permissions/thermometer.aspx. The page features the NCCN logo and the text "National Comprehensive Cancer Network CELEBRATING 20 YEARS Your Best Resource in the Fight Against Cancer®". A navigation bar includes links for Home, Visit the NCCN Patient Site, About NCCN, and Find a M. Below the navigation bar is a menu with categories: NCCN Guidelines®, NCCN Compendia, NCCN Templates®, Educational Events & Programs, Subscriptions & Products, Clinical & Business Resources, and NCCN Global. The "NCCN Guidelines®" category is selected, leading to the "NCCN Guidelines® & Clinical Resources" section. The main heading is "NCCN Distress Thermometer and Problem List". The content includes a thank you message, a permission statement, a disclaimer about commercial use, and information about translations and international adaptations. A sidebar on the left lists various NCCN resources and a "NCCN Compendium®" link is highlighted at the bottom.

Distress Thermometer and x

www.nccn.org/about/permissions/thermometer.aspx

Save to Mendeley

Home | Visit the NCCN Patient Site | About NCCN | Find a M

 National Comprehensive Cancer Network **CELEBRATING 20 YEARS**
Your Best Resource in the Fight Against Cancer®

NCCN Guidelines® **NCCN Compendia** **NCCN Templates®** **Educational Events & Programs** **Subscriptions & Products** **Clinical & Business Resources** **NCCN Global**

NCCN Guidelines®

NCCN Guidelines® & Clinical Resources

NCCN Distress Thermometer and Problem List

Thank you for your interest in the NCCN Distress Thermometer and Problem List, Figure (DIS-A), from the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Distress Management.

Permission is not required for the use, translation, or adaptation of the content within the NCCN Distress Thermometer and Problem List for personal use (including use with patients, in grants, or for research). If adaptations are being made to the NCCN Distress Thermometer or Problem List, all NCCN logos, trademarks, and names must be removed prior to production. If incorporating the NCCN Distress Thermometer and Problem List into an Electronic Health Record (EHR) system, use is approved for individual hospital use only and not for further distribution by the EHR vendor.

The NCCN Distress Thermometer and Problem List may not be used for any commercial purpose, including publication in journals, text books, etc., without the express written permission of NCCN. Permission may be requested by completing the [NCCN Permissions Request Form](#).

Download the NCCN Distress Thermometer and Problem List [HERE](#). By downloading this page you agree that you are a healthcare professional, researcher, hospital, or medical practice who will be using the NCCN Distress Thermometer and Problem List strictly for your personal use, which you represent and warrant being for non-promotional, educational use only.

NCCN has verified translations of the NCCN Distress Thermometer and Problem List in select languages. Approved international adaptations of the Distress Tool can be found at the [International Adaptations & Translations](#) section of NCCN.org.

If you would like to request permission to use the tool for any purpose other than direct treatment of patients or use in grants or research, please visit the [NCCN Permissions Request Form](#).

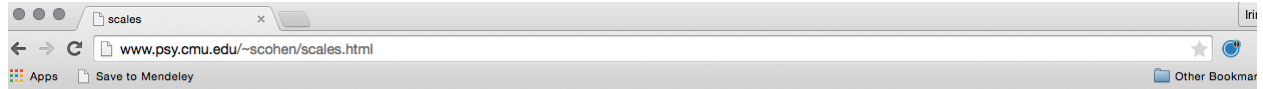
The National Comprehensive Cancer Network® (NCCN®) is a not-for-profit alliance of 26 of the world's leading cancer centers working together to improve the quality, effectiveness and efficiency of cancer care. At significant time and expense, NCCN has developed proprietary content for the provision of cancer care, including without limitation, the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®), the NCCN Guidelines for Patients®, the NCCN Drugs & Biologics Compendium (NCCN Compendium®), the NCCN Biomarkers Compendium®, and the NCCN Chemotherapy Order Templates (NCCN Templates®) (collectively, NCCN Content). NCCN Content is a valuable asset of NCCN and is subject to copyright, trademark and other legal protections. NCCN Content may not be used, copied, distributed or modified in any manner without a written license agreement from NCCN.

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- About The NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®)
- Development and Update of the NCCN Guidelines
- Recent Updates to NCCN Guidelines®
- NCCN Guidelines Panels - Meeting Schedule
- NCCN Categories of Evidence and Consensus
- NCCN Guidelines® Steering Committee
- Transparency: Process and Recommendations
- Submission Request to the NCCN Guidelines Panels
- Submission Request History
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2. Perceived Social Stress Scale



Dr. Cohen's Scales:

We welcome copies (e-mail is OK) of any in press or published papers using any of Dr. Cohen's scales that you are willing to share with us, and thank you in advance for your generosity. They will not be redistributed or linked without your permission.

Permissions: Permission for use of scales is not necessary when use is for nonprofit academic research or nonprofit educational purposes. For other uses, please contact the lab at commoncoldproject@andrew.cmu.edu for instructions.

3. Relationship Assessment Scale

Friday, May 22, 2015 at 12:40:38 PM Eastern Daylight Time

Subject: RE: Use of the Relationship Assessment Scale
Date: Friday, March 13, 2015 at 9:46:23 PM Eastern Daylight Time
From: Hendrick, S
To: Kolobova, Irina

Irina,

You have my full permission to use the Relationship Assessment Scale (RAS) in your dissertation. For your convenience, I have attached a copy of the scale (with scoring instructions), and two articles relevant to the scale's psychometric properties. In addition, I have done clinical work with cancer patients for many years and have a few articles that might be of interest to you at some point. So your topic, your program (Medical Family Therapy), and your ultimate success are of great interest to me.

Most Sincerely,
Susan Hendrick

Susan S. Hendrick, Ph.D.
Paul Whitfield Horn Professor of Psychological Sciences, Ret.
Texas Tech University
Adjunct Professor of Internal Medicine,
Texas Tech University School of Medicine

From: Kolobova, Irina [mailto:kolobovai13@students.ecu.edu]
Sent: Friday, March 13, 2015 6:36 PM
To: Hendrick, S
Subject: Use of the Relationship Assessment Scale

Good evening Dr. Hendrick -

I am a doctoral student in Medical Family Therapy at East Carolina University. Today, I am contacting you seeking to use the 'Relationship Assessment Scale' for my dissertation. I would like to administer it to young adult cancer patients and their caregivers to assess relationship satisfaction.

I look forward to your response.

Thank you,
Irina

Irina Kolobova, MA, CCRP
Medical Family Therapy Doctoral Student
East Carolina University
206.859.8317 cell
kolobovai13@students.ecu.edu

Note: This e-mail is intended for the individual(s) on the address line above. Please do not forward, copy, or disclose this communication to others without explicit approval of the author.

Page 1 of 1

4. Coping Strategies Inventory

Friday, May 22, 2015 at 12:42:58 PM Eastern Daylight Time

Subject: Re: Seek permission to use the The Coping Strategies Inventory Å Short Form

Date: Monday, March 16, 2015 at 1:18:59 PM Eastern Daylight Time

From: David Tobin

To: holroyd@ohio.edu, Kolobova, Irina

Dear Klobova,

Permission is granted to use the scale in your research. Just be sure to reproduce the copyright informatoin when you reproduce the scale.

Cheers,

David L Tobin, Ph.D., FAED
780 Chestnut St. Ste 12
Springfield, MA 01107
T 413-732-1717
F 413-732-5155

-----Original Message-----

From: Kenneth Holroyd <holroyd@ohio.edu>

To: Kolobova, Irina <kolobovai13@students.ecu.edu>

Cc: DAve Tobin <dvto2@aol.com>

Sent: Sat, Mar 14, 2015 11:47 am

Subject: Re: Seek permission to use the The Coping Strategies Inventory Å Short Form

Dear Kolobova:

Dr David Tobin (dvto2 @[aol.com](mailto:dvto2@aol.com)) can provide permission and materials. Best wishes with your work

Ken

Kenneth A. Holroyd, Ph.D.
Edwin & Ruth Kennedy Distinguished Professor of Psychology
200 Porter Hall
Psychology Department
Ohio University
Athens, OH 45701-2979
Ph: (740) 593- 1085, 1060
Fax: (740) 593- 0116
E-Mail: holroyd@ohio.edu
URL: <http://www.psych.ohiou.edu/labs/holroyd.html>

On Fri, Mar 13, 2015 at 7:52 PM, Kolobova, Irina <kolobovai13@students.ecu.edu> wrote:

Good evening Dr. Hendrick -

I am a doctoral student in Medical Family Therapy at East Carolina University. Today, I am contacting you seeking permission to use the "Coping Strategies Inventory"™ for my dissertation. I would like to administer it to young adult cancer patients and their caregivers to assess coping strategies.

I look forward to your response.

Thank you,
Irina

Irina Kolobova, MA, CCRP
Medical Family Therapy Doctoral Student
East Carolina University

5. Zarit Burden Inventory



User agreement
Special Terms

Mapi Research Trust, a non-for-profit organisation subject to the terms of the French law of 1st July 1901, registered in Carpentras under number 453 979 346, whose business address is 27 rue de la Villette, 69003 Lyon, France, hereafter referred to as "Mapi" and the User, as defined herein, (each referred to singularly as a "Party" and/or collectively as the "Parties"), do hereby agree to the following User Agreement Special and General Terms:

Mapi Research Trust
Information Support Unit
27 rue de la Villette
69003 Lyon
France
Telephone: +33 (0)4 72 13 65 75
Fax: +33 (0)4 72 13 66 82
Email: PROinformation@mapi-trust.org

Recitals

The User acknowledges that it is subject to these Special Terms and to the General Terms of the Agreement, which are included in Appendix 1 to these Special Terms and fully incorporated herein by reference. Under the Agreement, the Questionnaire referenced herein is licensed, not sold, to the User by Mapi for use only in accordance with the terms and conditions defined herein. Mapi reserves all rights not expressly granted to the User.

The Parties, in these Special Terms, intend to detail the special conditions of their partnership.

The Parties intend that all capitalized terms in the Special Terms have the same definitions as those given in article 1 of the General Terms included in Appendix 1.

In this respect, the Parties have agreed as follows:

Article 1. Conditions Specific to the User

Section 1.01 Identification of the User

User name	IrinaKolobova
Legal Form	Irina Kolobova
Address	East Carolina University Greenville, NC 27858
Country	United States of America

Name of the contact in charge of the Agreement	Irina Kolobova
Telephone number	2068598317
Fax number	
Email address	irinakolobova@gmail.com

if different:

Legal Form	
Address	
Country	

Section 1.02 Identification of the Questionnaire

Title	Zarit Burden Interview (ZBI)
Author(s)	Zarit Steven H, PhD
Owner	Zarit Steven H and Zarit Judy M

Copyright	Copyright 1980, 1983, 1990 Steven H Zarit and Judy M Zarit
Original bibliographic references	Zarit SH, Reeve KE, Bach-Peterson J. Relatives of the Impaired Elderly: Correlates of Feelings of Burden. <i>Gerontologist</i> . 1980;20(6):649-55 Zarit SH, Orr NK, Zarit JM. The hidden victims of Alzheimer's disease: Families under stress. New York: New York University Press, 1985 Zarit SH, Zarit JM. The Memory and Behavior Problems Checklist and the Burden Interview. Gerontology Center, Penn State University. 1990

Article 2. Rights to Use

Section 2.01 Context of the Use of the Questionnaire

The User undertakes to only use the Questionnaire in the context of the Study as defined hereafter.

Context of use	Other project
Title	Relationship Dynamics among Adolescent and Young Adults with Cancer and their Caregivers
Disease or condition	Cancer
Description of the project	Cross sectional, quantitative dissertation. Aims to examine relationship between caregiver burden and other relational dynamics between patients and their caregivers.
Presentation format of project	Dissertation

Section 2.02 Conditions for Use

The User undertakes to use the Questionnaire in accordance with the conditions for use defined hereafter.

(a) Rights transferred

Acting in the Author's name, Mapi transfers the following limited, non-exclusive rights, to the User (the "Limited Rights")

(i) to use the Questionnaire, only as part of the Study; this right is made up exclusively of the right to communicate it to the Beneficiaries only, free of charge, by any means of communication and by any means of remote distribution known or unknown to date, subject to respecting the conditions for use described hereafter; and

(ii) to reproduce the Questionnaire, only as part of the Study; this right is made up exclusively of the right to physically establish the Questionnaire or to have it physically established, on any paper, electronic, analog or digital medium, and in particular documents, articles, studies, observations, medical publications, websites whether or not protected by restricted access, CD, DVD, CD-ROM, hard disk, USB flash drive, for the Beneficiaries only and subject to respecting the conditions for use described hereafter; and

(iii) Should the Questionnaire not already have been translated into the language requested, the User is entitled to translate the Questionnaire or have it translated in this language, subject to informing Mapi of the same beforehand by the signature of a Translation Agreement and to providing a copy of the translation thus obtained as soon as possible to Mapi.

The User acknowledges and accepts that it is not entitled to amend, condense, adapt, reorganise the Questionnaire on any medium whatsoever, in any way whatsoever, even minor, without Mapi's prior specific written consent.

(b) Specific conditions for the Questionnaire

- Use in Individual clinical practice or Research study / project

The User undertakes never to duplicate, transfer or publish the Questionnaire without indicating the Copyright Notice.

- Use in a publication or on a website with unrestricted access:

In the case of a publication, article, study or observation on paper or electronic format of the Questionnaire, the User undertakes to respect the following special obligations:

- not to include any full copy of the Questionnaire, but a protected version with the indication "sample copy, do not use without permission"
- to indicate the name and copyright notice of the author
- to include the reference publications of the Questionnaire
- to indicate the details of Mapi Research Trust for any information on the Questionnaire as follows: contact information and permission to use: Mapi Research Trust, Lyon, France. E-mail: PROinformation@mapi-trust.org – Internet: www.proqolid.org
- to provide Mapi, as soon as possible, with a copy of any publication regarding the Questionnaire, for information purposes.

- Use for dissemination:

- On a website with restricted access:

In the case of publication on a website with restricted access, the User may include a clean version of the Questionnaire, subject to this version being protected by a sufficiently secure access to only allow the Beneficiaries to access it.

The User undertakes to also respect the following special obligations:

- to indicate the name and copyright notice of the author
- to include the reference publications of the Questionnaire
- to indicate the details of Mapi Research Trust for any information on the Questionnaire as follows: contact information and permission to use: Mapi Research Trust, Lyon, France. E-mail: PROinformation@mapi-trust.org – Internet: www.proqolid.org

- On promotional / marketing documents

In the case of publication on promotional/marketing documents, the User undertakes to respect the following special obligations:

- to indicate the name and copyright notice of the author
- to include the reference publications of the Questionnaire
- to indicate the details of Mapi Research Trust for any information on the Questionnaire as follows: contact information and permission to use: Mapi Research Trust, Lyon, France. E-mail: PROinformation@mapi-trust.org – Internet: www.proqolid.org
- to provide Mapi, as soon as possible, with a copy of any publication regarding the Questionnaire, for information purposes

For any other use not defined herein, please contact Mapi for the specific conditions of use and access fees (if applicable).

Article 3. Term

Mapi transfers the Limited Rights to use the Questionnaire as from the date of delivery of the Questionnaire to the User and for the whole period of the Study.

Article 4. Beneficiaries

The Parties agree that the User may communicate the Questionnaire in accordance with the conditions defined above to the Beneficiaries involved in the Study only, in relation to the Study defined in section 2.01.

Article 5. Territories and Languages

Mapi transfers the Limited Rights to use the Questionnaire on the following territories and in the languages indicated in the table below:

Language
English for the USA

Versions/Modules
ZBI - Zarit Burden Interview (22-items)

Article 6. Price and Payment Terms

The User undertakes in relation to Mapi to pay the price owed in return for the availability of the Questionnaire, according to the prices set out below, depending on the languages requested and the costs of using the Questionnaire, in accordance with the terms and conditions described in section 6.02 of the General Terms included in Appendix 1.

ROYALTY FEES *	Commercial users	Cost per study	1 000 €
		Cost per language	500 €
	Funded academic research	Cost per study	Free
		Cost per language	Free
	Not funded academic users	Cost per study	Free
		Cost per language	Free
DISTRIBUTION FEES *	Commercial users	Cost per study	1 000 €
		Cost per language	500 €
	Funded academic research	Cost per study	300 €
		Cost per language	50 €
	Not funded academic users	Cost per study	Free
		Cost per language	Free

* Excluding VAT

- *Commercial users: Industry, CRO, any for-profit companies*
- *Funded Academic research: Projects receiving funding from commerce, government, EU or registered charity. Funded academic research– sponsored by industry fits the “commercial users” category.*
- *Not funded academic users, individual medical practice: Projects are not explicitly funded, but funding comes from overall departmental funds or from the University or individual funds*

Agreed and acknowledged by

User's name: IrinaKolobova

Date:
13/03/2015

**APPENDIX D: LIST OF FACBEOOK
AND TWITTER ACCOUNTS**

Facebook Pages

13thirty cancer connect
15 -40 Connection
24 Hour Cancer Dance-a-thon
26.2 with Donna The National Marathon to
Finish Breast Cancer
A New Camino: A Latina's Journey Back
from Cervical Cancer
Action to Cure Kidney Cancer
Adolescent and Young Adult Cancer
Support
African Womens Cancer Awareness
Association
Allyson Whitney Foundation
American Association for Cancer Research
(AACR)
American Cancer Hope Lodge
American Cancer Society
American Cancer Society Cancer Action
Network - ACS Can
American Cancer Society Cancer Action
Network Arkansas - ACS CAN
American Cancer Society Cancer Action
Network Kentucky - ACS CAN
American Cancer Society Cancer Action
Network Maine - ACS CAN
American Cancer Society Cancer Action
Network Ohio - ACS CAN
American Cancer Society Cancer Action
Network Tennessee - ACS CAN
American Cancer Society Making Strides
Against Breast Cancer
American Cancer Society Making Strides,
Mid-South Division
American Cancer Society Relay for life
American Caregiver Collective
Asian & Pacific Islander National cancer
Survivors Network (APINCSN)
Athletes for a Cure
Babes Against Cancer
Babes Against Breast Cancer
Babes Against Breast Cancer - "Celebrity
Networking" Events
Be Bold, Be Bald
Be Child Cancer Aware
Be Loud Sophie Foundation
Be the Match
Be the Match - Patients Connect
Beat Cancer Boot Camp
Beat Cancer Movement
Beat Cancer Boot Camp - Wisconsin
Beat Cancer Boot Camp NW Tucson
Beat Cancer Boot Camp San Diego
Big Climb Seattle
Bone Marrow and Stem Cell Transplant
Survivors Club
BrainCancer.org
Breast Cancer African American - Sisters
Network, Inc
Breast Cancer Awareness - Positive
Promotions
Breast Cancer Awareness Body Painting
Project
Breast Cancer Awareness Month
Breast Cancer Can Stick It Foundation, Inc.
Breast Cancer Care
Breast Cancer Education Program-Wabash
County Illinois
Breast Cancer Now
Breast Cancer Survivors
Breathe Deep Bay Area
Bustin' Out - Empowering Young Adult
Breast Cancer Survivors
Cancer 180: Your Young Cancer
Connection
CancerApparelGifts.com
Cancer and Careers
Cancer Babes
Cancer Care Services
Cancer Caregivers Support Group
Cancer Caregiver Support & Humor
Cancer Caregivers
Cancer Caregivers Support Group
Cancer Caregiver Warriors
Cancer Center at Chops
Cancer Center Community Crusaders
Cancer Crusaders

Cancer Crusaders Nor Cal
 CANCER Crushers
 Cancer Dancer
 Cancer Education Program-Mayo Clinic
 Cancer Fighter Supporters
 Cancer Freeze
 Cancer Hope Network
 Cancer Research Institute
 Cancer Research Institute Young
 Philanthropists
 Cancer Schmancer
 Cancer Services, Inc.
 Cancer Services of Gaston County
 Cancer Smiles
 Cancer Sucks!
 Cancer Support Community
 Cancer Support community central Indiana
 Cancer Support Community Greater
 Philadelphia
 Cancer Support Community North Texas -
 Young Leadership Board
 Cancer Survivorship Coaching Coalition
 Cancer Survivors
 Cancer Survivors Park
 Cancer to 5K Training Program (thru
 Ulman)
 Cancer Warriors for Central Nevada
 Cancer Warriors Support Organization
 CancerCare
 CancerCon
 CancerConnect
 CancerConnects, Inc
 CancerForward: The Foundation for Cancer
 Survivors
 Cancerosity - Share your story, change a life
 CancerTruth
 Cape Fear Valley Health
 Caregiver
 Caregiver Action Network
 Caregiver Cafe
 Caregiver Stress
 Caregiving Cafe
 Caring Bridge
 Caring House
 Central Florida Young Breast Cancer
 Survivors Group
 Cervical Cancer
 Cervical Cancer Awareness
 Cervical Cancer Awareness
 Cervical Cancer my story so far
 Children's Cancer Research Fund
 Children's Flight of Hope
 Chris4Life Colon Cancer Foundation Young
 Professional Board
 Clark Family Breast Cancer Services, Inc
 Cleveland Hope Lodge
 Collaborative Family Healthcare
 Association
 Colon Cancer Alliance
 Colon Cancer Awareness
 Columbus Cancer Clinic Young
 Professional Group
 Comfycozy's for Chemo
 Connect4Cancer
 Cornucopia Cancer Support
 Crawl for Cancer - St. Louis and St Charles
 Critical Mass
 Cuck Fancer
 Dana-Farber Cancer Institute
 Dance Against Cancer
 Dancers for Cancer
 Dan's House of Hope
 Dear Jack Foundation
 Delete Blood Cancer
 Drive for the Cure of Cancer
 Duke Cancer Institute
 Duke Crush Colorectal Cancer 5k walk/run
 Dying to Live
 Eastern Shore Young Adult Cancer Alliance
 Eric. D. Davis Sarcoma Foundation
 Eyad Karkoutly Lymphoma Research
 Foundation
 FayToday - Fayetteville NC Community
 News
 Fight Kidney Cancer
 Free ME From Cancer
 FTL Sarcoma Fund
 Fuck Cancer
 Fuck Cancer
 Fxck Cancer
 Give Forward
 Glioblastoma Multiform Brain Cancer/GBM

Head and Neck Cancer Awareness
 Healthy Lives After Cancer
 Healthy Young Attitude
 Help Support women that have or have had
 ovarian cancer
 Hodgkin's Lymphoma Awareness (Group)
 Hope for Young Adults with Cancer
 Hope Lodge Lexington
 Huntsman Cancer Institute
 I Had Cancer
 I survived cancer
 iConnect: Young Adult Cancer Survivor
 Group
 Imerman Angels
 Infinity and Beyond
 International Chapter of Rights for Young
 People with Cancer
 International Firefighter Cancer Foundation
 It's a C Thing
 Jonny Imerman
 Keep a Breast and Young Survival Coalition
 Treasured Chest Program
 Keep Cancer Lame
 Keep it Natural - Beat Cancer Naturally
 Keychains for Cancer Research
 Kidney Cancer Association
 Kidney Cancer Awareness
 Kidney Cancer Awareness
 Kidney Cancer Awareness
 Kidney Cancer Awareness
 Kidney Cancer Support
 Kidney Cancer Support Network
 Kidney Cancer Warriors Support Group
 Koss National Triple Negative Breast
 Cancer Research Foundation
 Lacuna Loft
 Lauri Strauss Leukemia Foundation
 Leo Jenkins Cancer Center
 Leukemia & Lymphoma Society - Central
 CA Chapter
 Leukemia & Lymphoma Society - Michigan
 Chapter
 Leukemia & Lymphoma Society - Oregon,
 SW Washington, Idaho, Montana Chapter
 Leukemia & Lymphoma Society Idaho &
 Montana Branch

Leukemia & Lymphoma Society of
 Southern Nevada
 Leukemia & Lymphoma Society - Alabama
 / Gulf Coast Chapter
 Live for Today Foundation
 Livestrong
 Living Beyond Breast Cancer
 Living Beyond Breast Cancer's Reach and
 Raise
 LLS Advocacy
 LLS Light the Night Walk
 LLS Light the Night Walk (LLS Georgia
 Chapter)
 LLS Pennies for Patients - Rhode Island
 Chapter
 LLS SoCal Cancer Connection
 Los Angeles Patients and Caregivers Group
 (LAPCG)
 Lung Cancer Alliance
 Lung Cancer Alliance Pennsylvania Chapter
 Lung Cancer Caregiver and Family Support!
 Lung Cancer Survivors Foundation
 Lymphoma Research Foundation
 Making Strides Against Breast Cancer -
 Latina's Power
 Married with cancer
 Mary Shomon: Thyroid Cancer Patient
 Advocate, Author
 mAss Kickers Foundation
 MC Caregivers
 McConnell-Raab Hope Lodge
 MD Anderson Cancer Center
 Medical Family Therapy
 Miles Against Melanoma
 Miles Against Melanoma - Arizona
 Miles Against Melanoma Harrisburg PA
 Miles Against Melanoma NC
 Moffitt Cancer Center
 Multiple Myeloma Awareness
 Multiple Myeloma Awareness
 Multiple Myeloma Awareness
 Multiple Myeloma Research Foundation
 Multiple Myeloma Research Foundation -
 Team for Cures 5k Walk/Run Program
 My Little B's Have The Big C: A Breast
 Cancer Blog for Young Women

MyLifeLine.org Cancer Foundation
Nancy Marx Strength to Strength Cancer
Wellness Program
National Association of Social Workers
National Association of Social Workers -
Maryland Chapter
National Association of Social Workers -
North Carolina Chapter
National Association of Social Workers,
West Virginia Chapter
National Breast Cancer Awareness Fund
National Breast Cancer Coalition
National Breast Cancer Foundation
National Cancer Institute
National Cancer Survivors Day
National Young Adult Cancer Awareness
Week April 6-12, 2015
NCCC-National Cervical Cancer Coalition
NC YAC Family, Friends, & Caregivers
Nicki Leach Foundation
No-Shave November
North Carolina Chapter Society for Public
Health Education
North Carolina Chapter of the Leukemia &
Lymphoma Society
Orange Out Foundation
Ovarian Cancer 101
Ovarian Cancer Action
Ovarian Cancer Awareness Foundation
Ovarian Cancer Awareness in Loving
Memory of Beth York
Ovarian Cancer Awareness of Rochester
Ovarian Cancer National Alliance
Ovarian Cancer Support Page
Pancreatic Cancer Action Network
Pancreatic Cancer Action Network
Cincinnati Affiliate
Pancreatic Cancer Action Network
Pittsburgh Affiliate
PatientsLikeMe
Pennies for Patients: LLS MN, ND, SD &
WI
Pink Portrait Project
Pints for Prostates
Pittsburgh Beat Cancer Boot Camp
Pittsburgh Cure Sarcoma.org

Planet Cancer Book
Prayer Chain for anyone who has had cancer
touch their life
Prepare to Live
Prevent Cancer Foundation
Rare Kidney Cancer Association
Relay for Life of Bladen County
Relay for Life of Garner
Relay for Life of Northwest Tarrant County
Relay for Life of UNC-Chapel Hill
Relay for Life of UNC Charlotte
Rolfe Pancreatic Cancer Foundation -
Young Professionals Board
Rutledge Foundation
Sarcoma Foundation of America
Sandhills Young Adult Cancer Support
Group
Sarcoma Foundation of America - Texas
Chapter
Sarcoma Foundation of America South
Carolina Chapter
Sarcoma Foundation of America, Inc
Save the ta-tas
Sharsheret
Smile Bags- Bringing Smiles to Young
Adult Cancer Patients
Society for Adolescent and Young Adult
Oncology
StandUp2StupidCancer
Stick it 2 Cancer
Student Series - Leukemia & Lymphoma
Society OSWIM
Stupid Cancer
Stupid Cancer - Great Lakes;
Stupid Cancer - Northeast
Stupid Cancer - Pacific Northwest
Stupid Cancer - SoCal
Stupid Cancer - Southeast
Stupid Cancer - Texas
Stupid Dumb Breast Cancer
StupidCancer SDSU
Support the Fight Against Breast Cancer
Supporters of Brain Cancer Awareness
Supporters of Sarcoma Awareness
Susan G Komen
Susan G Komen Austin

Susan G Komen Colorado
 Susan G Komen Columbus
 Susan G Komen for the Cure Greater Nashville
 Susan G Komen Greater Fort Worth
 Susan G Komen Greater Kansas City
 Susan G Komen Greater New York City - Young Professionals
 Susan G Komen Greater NYC
 Susan G Komen Michigan, Mid-Michigan Office
 Susan G Komen Tidewater
 T-Cell Leukemia Lymphoma Foundation
 Teal Butterfly Challenge. Ovarian Cancer Awareness
 Team in Training
 Team in Training - North Carolina
 Team in Training Greater Bay Area Chapter
 Team in Training Greater Sacramento Area Chapter
 Team in Training NYC Chapter
 Team in Training OSWIM Chapter
 Team in Training Washington Alaska Chapter
 Teen Cancer America
 Teens Living with Cancer
 Teens Living with Cancer Buffalo
 Teens Living with Cancer DC
 Terry's Big Adventure
 Testicular Cancer Foundation
 Testicular Cancer Awareness Foundation
 Testicular Cancer Awareness Network
 Testicular Cancer Society
 The Andy Talley Bone Marrow Foundation
 The answer to cancer
 The Bone Marrow Foundation
 The Breast Cancer Site
 The Brent Schoening Strikeout Leukemia Foundation
 The Cancer Exchange
 The Caregiver Space
 The Cassie Hines Shoes Cancer Foundation
 The Colon Club
 The Duke Cancer Patient Support Program
 The Half Fund
 The Hodgkin's Lymphoma Violet Ribbon Shop
 The Intentional Caregiver
 The Intentional Mom
 The Jared Box Project
 The Leukemia & Lymphoma Society - Mid-America Chapter
 The Leukemia & Lymphoma Society - SC
 The Leukemia & Lymphoma Society (National page)
 The Leukemia & Lymphoma Society CT Westchester Chapter
 The Leukemia & Lymphoma Society Long Island Chapter
 The Leukemia & Lymphoma Society New York City Chapter
 The Leukemia & Lymphoma Society Washington/Alaska Chapter
 The Leukemia & Lymphoma Society, Georgia Chapter
 The Leukemia & Lymphoma Society, Indiana Chapter
 The Leukemia & Lymphoma Society, Massachusetts Chapter
 The Leukemia & Lymphoma Society, Minnesota
 The Leukemia & Lymphoma Society, Northern Central Florida Chapter
 The Leukemia & Lymphoma Society, Savannah Georgia
 The Leukemia & Lymphoma Society, Wisconsin Chapter
 The Lymphoma Club
 The Moyer Foundation
 The Paula Takacs Foundation for Sarcoma Research
 The Richard M. Schulze Family American Cancer Society Hope Lodge
 The SAMFund for Young Adult Survivors of Cancer
 The Steven G. AYA Cancer Research Fund
 The V Foundation for Cancer Research
 Thyroid Cancer Survivors
 Triage Cancer
 U27 Survivorship Group - Young Adult Cancer Support

Ulman Cancer Fund for Young Adults
Ulman Cancer Fund for Young Adults:
Terps Against Cancer
Voices of Survivors
WAKA Kickball
Wake Forest Community Information
Warrior Angels Breast Cancer Battle
Buddies Inc
Weill Cornell Leukemia Program
WellBeyondThis
Western Michigan Leukemia and
Lymphoma Society
Win the Fight Against Cancer
Women Cancer Warriors
Working with Cancer, Illness & End of Life:
a continuing education program
YAALL - Young Adults Against Leukemia
and Lymphoma
YACS Pittsburgh
Young Adult Cancer Connection
Young Adult Cancer Fighters of Tulsa
Young Adult Cancer Foundation
Young Adult Cancer Group
Young Adult Cancer Survivors
Young Adult Cancer Survivors of Atlanta
Young Adult Cancer Survivors of Smith
Center
Young Adult Cancer Survivors, Central
Pennsylvania
Young adult caregivers
Young Adult Kidney Cancer Survivors
Young Adults Affected by Cancer
Young Adults and Caregivers Coping with
Cancer in Wilmington, NC
Young Adults Fighting Cancer
Young Adults Surviving Glioblastoma
Young Adults with Cancer
Young Friends of the Abramson cancer
Center
Young Pink Sisters Charity
Young Professionals for the American
Cancer Society - Memphis
Young Sisters Initiative - Breast Cancer
Survivors
Young Survival Coalition
Young Survival Coalition Northeast Region

Young Survival Coalition South Region
Young Survival Coalition West Region
Young Texans Against Cancer - Austin
Chapter
Young Women Surviving Breast Cancer
Day on Capitol
Young Women's Breast Cancer Program in
St. Louis
Young Womens Breast Cancer Awareness
Foundation
Young Womens Breast Cancer Program in
St. Louis
Young Women Get Breast Cancer
YPC - Leukemia & Lymphoma Society, NJ
Chapter

Twitter Accounts

1540 Connection	COPING_cancer	pewresearch
1ballerina	DansHouseofHope	preventcancer
AACR	dearjackhq	preventcancernew
ABC_program_	determined2cure	QuitCancer
aFreshChapter	familyhousesf	rckAganstCancer
AmyMAustinMktg	FCancerNow	RutledgeFndn
AndiOhal	FightCancerNow	savethecheeks
AnnieAppleseed	FocusonCancer	seventyk
AYASurvivorship	FrankiesMission	sexyaftercancer
AZCancerCenter	FredHutch	SHAREing
BCAcampaign	FUbreastcancer	SherryLAbbott
BCAction	FWAYAOC	singlejingles
BCRFcure	FxCKCANCER	sloan_kettering
BCSMChat	getswabbed	stevegfund
Becs Troops	gynesm	Stupid Cancer
BeTheMatch	HelenBurmester	StupidCancerCEO
Beyond_Cancer	HernanTCA	swog
BreakCancer	Hope4WC	tambreighn
breastcancer	jackiefox12	TeenCancerUSA
breastcancerclu	JackysKids	The Good Breast
BreastCancerH	JonnyImerman	theABTA
Breastcancerorg	kairol	theasphere
caissg	KayCancerFree	theCGspace
Cancer_Buzz	keepabreast	theNCI
CancerAdvocacy	lanisia	TheRealMalfoy85
CancerBeGlammed	LDisner	Thrive_Org
CancerForward	lynnm7417	tjmartell
CaregiverAction	MattieMiracleCF	TrudeauHern
CaregiverAlly	MHBTmovie	UnmasqueCancer
Caregiverus	NCISymptomMgmt	uvmer
CaregiverTweets	NYTHealth	YACancerConnect
CheckThemBret	nytimeswell	YACSpittsburgh
chemobrainfog	OHSUaya	YSCBuzz
ChemobtwClasses	patientchat	YWBCP