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LOMA LINDA UNIVERSITY
School of Behavioral Health
Department of Psychology

Program Evaluation and Guideline Development for Psychological Treatment of the Adolescent and Young Adult Population with Cancer

by
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Project submitted in partial satisfaction of
the requirements for the degree of
Doctor of Psychology

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ABBREVIATIONS

AYA	Adolescent and Young Adult
AYAO	Adolescent and Young Adult Oncology
NCI	National Cancer Institute
UPMC	University of Pittsburgh Medical Center
USC	University of Southern California
NCCN	National Comprehensive Cancer Network

ABSTRACT

Program Evaluation and Guideline Development for Psychological Treatment of the Adolescent and Young Adult Population with Cancer

by

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Doctor of Psychology, Graduate Program in Psychology
Loma Linda University, September 2015
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The adolescent and young adult (AYA) cancer population suffers from many unique medical and mental health challenges. Both medical, psychological and support services play an important role in the lack of improvement in survival rates of this population. The purpose of this project was to identify the unique mental health challenges and treatment needs of the Adolescent and Young Adult (AYA) Oncology population and to evaluate current oncology programs available to this population at Loma Linda University. The project provides guideline recommendations for implementing a comprehensive and developmentally appropriate AYA oncology program at Loma Linda University.

TABLE OF CONTENTS

Page

Chapters:

CHAPTER 1

INTRODUCTION

The adolescent and young adult (AYA) cancer population suffers from many unique medical and mental health challenges. According to the National Cancer Institute (n.d.), each year 70,000 adolescents and young adults are diagnosed with cancer. Among the AYA population (ages 15-39), cancer is the leading cause of disease-related death among females and second to heart disease among males (National Cancer Institute, 2013). Survivorship is an important goal for the cancer population and a concerning statistic for the AYA population. Within the last 30 years, both pediatric and older age groups with cancer have seen improvements in survival rates, yet survival rates for AYAs have failed to improve (NCI, 2013; Williams, 2013; Bleyer, 2011). Both medical, psychological and support services play an important role in the lack of improvement in survival rates of this population. In looking at medical treatment outcomes and declined improvement in survival rates of the AYA population, adherence issues, biological differences (Williams, 2013; Bleyer, 2011), access to healthcare insurance and services (Bleyer, 2011; U.S. Department of Health and Human Services, National Institutes of Health, National Cancer Institute, & LIVESTRONG Young Adult Alliance, 2006), lack of research (Williams, 2013; U.S. Department of Health and Human Services et al., 2006), restricted access to care, delays in diagnosis, inconsistency in treatment and follow-up care (U.S. Department of Health and Human Services et al., 2006) and distinctive psychosocial and supportive care needs (Bleyer, 2011) play the greatest role. A possible solution to survival rate stagnation and improvement in total healthcare for this population is the utilization of integrated AYA specific healthcare programs allowing access to a needed variety of services aimed at this population.

The AYA cancer population faces unique medical and psychological treatment needs compared to older and younger populations. The AYA population's medical treatment is often divided between pediatric and older adult treatment entities and specific medical needs are often not addressed in a subspecialty within oncology services (Williams, 2013). The creation of a medical subspecialty has been purposed (Williams, 2013) as well as the creation of multidisciplinary teams encompassing both pediatric and adult practitioners (Bernig et al., 2013). The medical subspecialty field of Adolescent and Young Adult Oncology (AYAO) has obtained increased focus in the healthcare field (Hayes-Lattin, Mathews-Bradshaw, & Siegel, 2010; Thomas, Albritton, & Ferrari, 2010; Steinbeck, Towns, & Bennett, 2014) while the AYA population has a unique set of medical and mental health needs that may better be addressed by utilizing a multidisciplinary approach (Williams, 2013). Furthermore, research suggests that personnel treating the AYA population should be formally trained to address the unique medical and psychosocial needs of the AYA population and provide specialized oncology care (Zebrack, Mathews-Bradshaw, & Siegel, 2010). Despite the identified importance of integrated AYA healthcare programs and specialized AYA healthcare teams, few programs have been implemented. This has however slowly begun to change as comprehensive AYAO programs have begun to take shape in many countries around the world (Ferrari et al., 2010). Although limited programs are currently in practice, the medical field is increasing their integration of medical and mental health treatment and many intact programs and AYA organizations are creating AYA specific treatment guidelines to meet patient needs.

CHAPTER 2

THEORY

Developmental theory is a key element to understanding the developmental stages of the adolescent and young adult oncology population in order to accurately focus psychological care. Of the multiple developmental theories in the literature, Erikson's Theory of Psychosocial Development is most often referenced.

Erik Erikson's Theory of Psychosocial Development

One of the most popular and highly acclaimed theories of development over the life span is Erikson's Theory of Psychosocial Development. Overall, Erikson's theory is compromised of eight stages that individuals progress through from their birth until death. Erikson believed that in each stage new challenges occur that test an individual's identity (Fleming, 2004). Erikson labeled these challenges, crises (Fleming, 2004). Erikson believed that maturation effects and social demands drive individuals through each developmental stage (Sigelman & Rider, 2009), and only by overcoming crises does one obtain successful psychosocial development (Fleming, 2004). Although Erikson's theory covers the entire lifespan, the AYA populations' development would fall within stages applicable to individuals ages 15-39. These include Stage Five, Identity vs. Role Confusion (12-20 years old) and Stage Six, Intimacy vs. Isolation (20-40 years) (Sigelman & Rider, 2009).

Stage Five Identity vs. Role Confusion

Stage Five of Erikson’s Theory of Psychosocial Development occurs during adolescence and within the age range of 12-20 years old (Sigelman & Rider, 2009). The main crisis within this stage is defining who the individual is and their role in the future (Holloway, Holloway, & Witte, 2010; Sigelman & Rider, 2009). During this stage, individuals define and create an identity while also individuating themselves from their parents (Fleming, 2004). Overall, the added stressor of having cancer creates significant challenges to individuation. Without proper treatment and services offered to support the AYA population it is possible that proper development will not occur.

Stage Six Intimacy vs. Isolation

Stage Six of Erikson’s Theory of Psychosocial Development occurs within the age range of 20-40 years old (Sigelman & Rider, 2009). This stage in Erikson’s theory is based upon intimacy with another individual, including closeness and sharing of personal insights (Fleming, 2004; Holloway et al., 2010). This intimacy between two people can only be achieved if identity is fully developed by both parties (Fleming, 2004) otherwise relationships remain superficial (Holloway et al., 2010). Intimacy is particularly challenging for the AYA oncology population due to the physical and psychological effects of cancer.

CHAPTER 3

EFFECTS ON DEVELOPMENT

The AYA oncology population suffers from multiple physical and psychological effects from cancer treatment and diagnosis. For adolescents with chronic illness biological, psychological and social effects are likely to impair or change the course of normal development (Suris, Michaud, & Viner, 2004). Research suggests that chronic illness can delay puberty for adolescents, prolong egocentricity into late adolescence, increase the development of sexual identity and body image issues, impair cognitive functioning, reduced independence from others, increase social isolation, and lead to educational and vocational delays and failures (Suris et al., 2004; Holmbeck, 2002). Developmental issues vary by illness. For the AYA oncology population these issues include, family relationship concerns, sexuality and reproductive issues, peer relationships, body image concerns, school disruption and career development (Roberts, Turney, & Knowles, 1998; Eiser, Penn, Katz, & Barr, 2009; Zebrack, Hamilton, & Smith, 2009; Epelman, 2013; Evan & Zeltzer, 2006; Ettinger & Heiney, 1993), as well as risky behaviors and medication adherence issues (Jones, 2008; Kondryn, Edmondson, Hill, & Eden, 2009; Morgan, Davies, Palmer, & Plaster, 2010; Butow et al., 2010). Although the categories can be looked at in isolation, often these issues are intertwined, having an effect on one another and healthy developmental progression.

Family and Peer Relationships

Family and peer relationships are important for the AYA oncology population however, this area of development often faces many challenges. Familial relationships are a source of support for adolescents and young adults as well as a key area of normal developmental changes. During adolescence, normal development depicts adolescents engaging in individuation from parental figures (D'Agostino, Penney, & Zebrack, 2011). Individuation from parent figures for the AYA population brings increased difficulties, unlike healthy peers, due to the AYA population having increased reliance on their parents (D'Agostino et al., 2011). This lack of independence from an individual's family may be due to health insurance reasons, illness maintenance, and parental overprotection (Suris et al., 2004; Ettinger & Heiney, 1993; Roberts et al., 1998). For this population there is often a struggle between dependency and individuation. The dependency struggle can be seen as an AYA youth wanting parental comfort when feeling ill and then rejecting parental comfort in relation to their illness when the AYA youth feels well (Ettinger & Heiney, 1993). Adolescents and young adults with cancer may in fact rebel against dependency with hostility towards family members or treatment refusal (Roberts et al., 1998). Developmentally, the AYA oncology population seeks independence from familial relationships but medical necessities hinder individuation of this population potentially stunting developmental growth for the AYA population.

The AYA oncology population also struggles with within family relationships that potentially negatively affect the youths' developmental course. When a youth is diagnosed with cancer, the entire family is impacted by the illness. Overall, family cohesiveness is an important factor to positive adjustment for the AYA youth to their cancer diagnosis (Zebrack, 2011) and therefore family functioning is important to the AYA's perceived distress and mental health. Within the family, family roles are likely to change, for example a family member becomes more like a caregiver, and these role changes may impact family finances due to increased caregiving activities (Roberts et al., 1998). Often the AYA youth feels burdensome within the family system and the youth may believe it is most appropriate for the youth to appear strong and capable of coping with medical and psychological effects of treatment even if this is inaccurate (Ettinger & Heiney, 1993). Issues that affect family members and family functioning are likely to affect the youth's adjustment to illness and perception of illness related outcomes ultimately potentially delaying appropriate developmental milestones for the AYA youth.

In terms of individuation, the identity process of the AYA youth relies on the individual interacting and utilizing peer groups however, this is more difficult to achieve for an individual with a chronic illness (Suris et al., 2004). Sustaining peer interactions is vital for this population to continue normal developmental progression (D'Agostino et al., 2011; Suris et al., 2004) however, due to long-term hospitalizations, missing peer activities, and peer group exclusions, important peer relationships may not be in place for the AYA individual to utilize in order to help with identity formation and independence (Suris et al., 2004). Often, the AYA youth may become excluded from their peer group (Suris et al., 2004) and feel an increased level of social isolation (Ettinger & Heiney, 1993; Roberts et al., 1998; Zebrack, 2011). An adolescent or young adult with cancer may have periods of hospitalization or illness that keep them from engaging with same-age peers (Morgan et al., 2010). During this time the individual's peer social groups may evolve in their absence, and the patient may become more socially isolated (Morgan et al., 2010). Additionally, encouraging the AYA population to develop or continue relationships with same age peers can help promote healthy identity development for the AYA patient (Zebrack, 2011). The AYA youth is at risk for missing normal AYA life activities such as college, employment, marriage and having children (Zebrack, 2011) and it is developmentally important that the AYA youth is given the opportunity to engage in normal school and AYA life activities (Ettinger & Heiney, 1993; Roberts et al., 1998; Zebrack, 2011). Increasing the AYA individual's opportunities to engage in developmentally appropriate social interactions in just as important to proper development as increasing the youth's ability to create meaningful relationships with peers.

The AYA individual is likely to experience issues relating to same age peers. Not only do lack of social interactions due to illness affect the youth's sense of individuation, it also decreases an AYA individual's ability to be intimate with others (Eiser et al., 2009). AYA youth have difficulties sharing information about their illness and are often unsure what information to disclose to peers about their illness for fear that friends may treat the youth differently (Ettinger & Heiney, 1993). AYA oncology youth express increased levels of anxiety and uncertainty in regards to sharing illness information with other youth (Zebrack, 2011) therefore, may experience increased levels of distress when unsure how others will respond to their illness. Within social relationships, healthy peers may feel sorry for the AYA youth and view them as fragile (Evan, Kaufman, Cook, & Zeltzer, 2006) whereas other healthy peers may tease the AYA youth, avoid them or treat them as outcasts (Roberts et al., 1998). AYA individuals find maintaining peer relationships difficult (Roberts et al., 1998) however, increasing the youth's peer interactions and interpersonal skills are likely to help the youth continue on an appropriate developmental trajectory.

Sexuality and Reproduction

Intimacy is particularly challenging for the AYA oncology population due to sexuality and fertility issues. Outside of the physical impact of cancer treatment, reproductive changes also have impact on an adolescent's self-concept, peer relationships, psychosexual development and sexual activity (Roberts et al., 1998). The AYA population expresses developmentally appropriate desires to establish intimate relationships with others (Ettinger & Heiney, 1993) however, developing romantic relationships may be put on hold for this population due to feeling unattractive or different, fearful of exposing their diagnosis, and overall poor development of social skills (Evan et al., 2006). Despite sexual intimacy being important for the AYA youth's quality of life (Zebrack, 2011), AYA individuals have a decreased sexual self-image compared to their healthy peers (Roberts et al., 1998). Altered physical appearance, impaired sexual performance (Roberts et al., 1998), and lack of knowledge of how to be intimate with others (Evan et al., 2006) could lead the youth to feel fear of rejection by intimate partners and pessimism about sexual relationship possibilities (Zebrack, 2011). Furthermore, AYA oncology youth may be less likely to explore his/her sexual orientation, most notably feelings of homosexuality due to perceived increased levels of hardship already present in their lives in relation to the cancer diagnosis (Evan et al., 2006). Developmentally, the effect of physiological and psychological changes may have negative effects on interpersonal intimacy for the AYA oncology population.

Not only are romantic relationships important for the normal development trajectory of the AYA oncology population, but fertility is also of concern for the population. Fertility concerns differ for males and females (Roberts et al., 1998) but ultimately stem from an individual’s apprehensions about infertility, family planning, and sexual relationships (D’Agostino et al., 2011). The expressed concerns for cancer related fertility are often associated with high rate of distress, depression and grief within the population (Murphy et al., 2013). In treatment, proper support should not only be given surrounding the medical implications of treatment on fertility and sexuality but also psychologically how these may affect current and future romantic relationships and families.

Body Image

During adolescence and young adulthood, an individual’s appearance is of great importance. Individuals within the AYA population experience changes in appearance and difficulties with body image, both of which may have great effect on the youth’s mental health (Baker et al., 1993; Epelman, 2013; Zebrack, 2011) as well as their identity development. Often changes in appearance for the AYA oncology population are due to treatment effects or cancer progression. Many oncology youth display concerns over hair loss and regrowth (Ettinger & Heiney, 1993; Roberts et al., 1998; Lewis, 1996; Evan et al., 2006). Concerns over hair loss are seen as more distressing for females than for male AYA oncology youth (Roberts et al., 1998). AYA youth with cancer display altered self perceptions in regards to body image and are concerned with looking physically different from one’s peers (Ettinger & Heiney, 1993; Roberts et al., 1998; Lewis, 1996; Evan et al., 2006) therefore likely to increase distress in the AYA oncology population. Other physical changes for this population include weight loss or gain (Ettinger & Heiney, 1993; Roberts et al., 1998; Lewis, 1996; Evan et al., 2006), treatment and/or surgery scars, and loss of body parts (White, 2000). Although many of these concerns are not unique to the AYA oncology population, body image and acceptance are important developmental aspects of an adolescent and young adult. Therefore, body image issues are likely to have a greater impact on the AYA population’s healthy developmental trajectory and concerns are likely to impact the psychological well being of these individuals.

School Disruption and Career Development

The adolescent and young adult oncology population often encounters disruptions in academic and career development. Due to an individual’s illness and treatment, the AYA oncology youth may experience a conflicting relationship between illness management and academics (Suris et al., 2004). Youth with cancer are more likely to miss or skip school due to treatment and cancer related issues (Roberts et al., 1998) and yet may in turn miss treatment because academics are deemed more important (Suris et al., 2004). This conflict has a negative effects on development as the youth may miss out on important academic and social aspects of school, as well as missing out on the medical benefits of cancer treatment. The AYA oncology youth may also miss school due to increased time spent in the hospital (Suris et al., 2004) and long school absences may make the return to school more difficult for the youth (Roberts et al., 1998). School is important not only for intellectual development but also exposes the youth to key social interaction that are developmentally important for the AYA youth’s individuation process. Physical changes and body image may invoke feelings of embarrassment that may further avoidance of school and social activities (Roberts et al., 1998). Academics are important for the AYA population and the transition from school to work is also greatly affected by youth's cancer diagnosis.

Within the developmental period of adolescence and young adulthood, the youth undergoes multiple challenges in identifying future goals related to education and occupation. AYA oncology youth display concerns about future life goals (Zebrack, 2011; Ettinger & Heiney, 1993) most notably future career goals (Ettinger & Heiney, 1993). Developmentally, the transitional period between school and work is a typical developmental task that helps secure adult identity (Nurmi & Salmela-Aro, 2002). Occupation and career exploration is an important developmental task for adolescents and young adults however, the AYA oncology population is likely to experience altered career exploration and is more likely to display a foreclosed identity formation (Stern, Norman, & Zevon, 1991). According to literature this identity foreclosure is likely adaptive in nature, since AYA oncology youth experience uncertainty of living and therefore may feel greater pressure to decide a career path without extensive exploration (Stern et al., 1991). Along with career related identity issues, the youth may also exhibit financial concerns and workplace related issues.

Financial and workplace concerns are important aspects of the AYA youth's developmental trajectory as they may create increased distress for individuals and delay developmental progression. The adolescent and young adult oncology population displays multiple financial concerns (Zebrack, 2011; Ettinger & Heiney, 1993) that vary by environmental factors and developmental stages. Financially, some youth are still dependent on his/her parents (D'Agostino et al., 2011) and therefore financial concerns are a family burden somewhat less dependent on the youth's occupational path. For the

AYA young adult developmentally past familial individuation, the young adult may have financial concerns such as loss of an income due to treatment and inability to work, difficulties obtaining and maintaining jobs post treatment, as well as unfair bias and discrimination in the workplace (D'Agostino et al., 2011). A study by Parsons et al. (2012), suggests access to medical insurance may have an effect on the youth's engagement in the workplace as this research shows AYA youth who are uninsured before diagnosis are significantly less likely to work full time after treatment than those who had insurance provided by an employer or school. Overall, the adolescent and young adult population with cancer displays many struggles that are likely to have an effect on normal developmental progression and may increase psychological distress for this population.

Risky Behaviors and Medication Adherence

Developmentally, adolescence and young adulthood is a time for exploration. Due to brain development and environmental factors this exploration may lead to risk taking behaviors and medical non-compliance. Adolescents and young adults have a poor ability to imagine future consequences and poorly developed planning skills, all which increase the youth's susceptibility for medical non-compliance (Suris et al., 2004). Furthermore, medication non-compliance may be a manifestation of discord in health beliefs and goals between medical professionals and the youth (Suris et al., 2004). Acceptance is important during this developmental period therefore, treatment side effects and a need for peer acceptance can also lead to medication non-compliance (Suris et al., 2004). Other reasons for non-compliance include lack of resources, fear of treatments and side effects, and poor understanding of treatment regimen or the seriousness of one’s illness (Spinetta et al., 2002). Since the AYA oncology population is at risk for higher levels of death due to illness, medical compliance is a pressing issue to insure proper healthcare.

Adolescents and young adults engage in exploratory behaviors that can lead to risk taking behaviors. For the AYA oncology youth, these risk taking behaviors can interfere with medical treatment (Jones, 2008; Morgan et al., 2010) and lead to detrimental health decline and possible secondary cancers (Jones, 2008). Literature suggests survivors of adolescent cancer are at an increased risk for substance use and risky sexual behaviors (Jones, 2008). According to literature, risky sexual behaviors may be related to the AYA youth’s beliefs that he/she is infertile due to treatment (Murphy et al., 2013). Physiologically, the AYA oncology youth is more susceptible to sexually transmitted infections because of cancer treatments and therefore are at greater risk for acquiring increased health difficulties due to these risk-taking behaviors (Murphy et al., 2013). Within the AYA oncology population, alcohol use is also of concern (Pratt-Chapman, Wills, Bretsch, & Patierno, 2013; Morgan et al., 2010) as well as tobacco, engagement in physical activity, and unprotected sun exposure (Pratt-Chapman et al., 2013). Risk taking behaviors pose a threat to the AYA youth’s ongoing medical cancer treatment and leads them open for future health complications.

CHAPTER 4

PSYCHOLOGICAL DISTRESS

With increased opportunities for developmental trajectory delay, the AYA cancer population is likely to feeling increased levels of psychological strain. The AYA cancer population displays heightened levels of psychological risk factors that may lead to the development of psychological distress. Overall, youth with chronic conditions like cancer, are more likely to display internalizing symptoms and are at higher risk for developing at least one psychiatric diagnosis (Suris et al., 2004). A study by Zabora, Brintzenhofeszoc, Curbow, Hooker, & Plantadosi (2001), estimated higher levels of stress occurred in younger cancer patients (<30 years old) relative to older patients with cancer ranging in age from 30-95 years old. According to Dyson, Thompson, Palmer, Thomas, & Schofield (2012), approximately 25% of the AYA population suffers from significant psychological distress however, literature suggests that the AYA population does not suffer from higher levels of depression and anxiety than their healthy peers (Allen, Newman, & Souhami, 1997; Neville, 1998). In fact, the AYA population has been noted in literature as extremely resilient despite a number of stressful factors present in their lives (Larsson, Mattson, & Von Essen, 2010). Depression and anxiety in this population are influenced by the presence of multiple illness risk factors. Research suggests that the prevalence of psychological distress may vary during cancer treatment after the initial cancer diagnosis for adolescents and young adults with cancer (Larsson et al., 2010; Jorngarden, Mattsson, & Von Essen, 2007; Kwak et al., 2013; Dyson et al., 2012). Literature suggests that the AYA population suffers from significantly higher rates of distress compared to healthy peers at their initial cancer diagnosis but distress appears to decrease over the course of treatment and after treatment is completed (Jorngarden et al., 2007; Larsson et al., 2010; Kwak et al., 2013). Although past research suggests a steady decrease in distress levels over the course of treatment (Jorngarden et al., 2007; Larsson et al., 2010), newer research suggests that AYA youth experience high levels of distress at the time of their diagnosis and at the time of transition to survivorship (Kwak et al., 2013). Longitudinally speaking however, all research in regards to the distress levels of this population suggest that despite spikes in distress relative to time in treatment and treatment phase the AYA population is less distressed 1 year (Kwak et al., 2013), 1.5 years (Jorngarden et al., 2007), and 4 years (Larsson et al., 2010) after their initial diagnosis. With knowledge of the different peaks of distress within the AYA population, psychological treatments and referrals can better identify and target the clinical needs for the AYA youth.

Distress for the AYA population is likely linked to developmental tasks and trajectory setbacks. Although literature suggests that developmental periods are important for psychological wellbeing of the AYA oncology population, there are limited studies that discuss distress trajectories and their association with developmental processes. In a study by Kwak et al. (2013), it is suggested that distress within the AYA population peaks twice during their disease treatment, first shortly after diagnosis and second during the transitions to survivorship. Research confirms that AYAs are at greatest risk for anxiety and depression during the critical period between diagnosis and onset of treatment (Dyson et al., 2012). Developmental contributions are critical to understand as they offer insight into treatment goals and interventions necessary to help this population thrive psychologically. Often during treatment AYA youth are experiencing adverse treatment effects and concerns as well as changes in physical appearance, all which are linked to increased levels of distress in AYA youth (Kwak et al., 2013). Post treatment and during the transition into survivorship youth experience health uncertainties, employment and academic disruptions and transitions, financial difficulties and social reintegration, all sources of distress for the youth (Kwak et al., 2013). Furthermore, according to Neville (1998), ambiguity of illness state and cancer treatment complexity are also linked with having greater levels of psychological distress. Various factors such as the number of treatment types, undergoing chemotherapy and current cancer-related symptoms also predicted levels of depression while stressful life events, and fewer types of treatment were greater predictors of anxiety for this population (Deimling, Kahana, Bowman, & Schaefer, 2002). Further research is needed to solidify a proper understanding of distress and its link to developmental trajectory delays.

Psychological Distress and Unmet Needs

During all stages of treatment, including pre and post treatment, developmental transitions are key to understanding one aspect of AYA population distress. To create comprehensive treatment guidelines for the AYA oncology youth it is important to understand the AYA population’s needs for which he or she must meet for successful treatment and transition to survivorship. Psychological distress is also associated with having unmet physical and psychosocial needs (Dyson et al., 2012). Unmet physical and living needs were shown in literature to be main predictors of depression, while unmet health systems and information needs predicted state anxiety (Dyson et al., 2012). With a variety of factors propagating psychological distress, including treatment phase, illness symptoms, and unmet needs, psychological services should be further integrated into the comprehensive care of the AYA patient in order to improve quality of life and emotional wellbeing.

Psychological Needs

Specific mental health challenges faced by the AYA population include anxiety associated with potential recurrence (Baker et al., 1993; Cincotta, 1993), an increased risk for psychosocial difficulties (Woodgate, 2005), difficulties accessing psychosocial services (Keegan et al., 2012), shifts in educational and occupational outcomes (Baker et al., 1993; Epelman, 2013), negative effects on sexuality (Morgan et al., 2010; Epelman, 2013; Zebrack, 2011) and fertility (Morgan et al., 2010; Epelman, 2013; Zebrack, Casillas, Nohr, Adams, & Zelter, 2004), difficulties with body image (Baker et al., 1993; Epelman, 2013; Zebrack, 2011) and limits of social support (Zebrack, Mills, & Weitzman, 2007). Integrated healthcare targeted at the AYA population may help to improve survivorship and increase the quality of medical and mental healthcare for the AYA population. Overall, few programs are aimed at addressing the increased number of informational, psychosocial, and practical support needs of the AYA population (Zebrack et al., 2013; D’Agostino et al., 2011). The most commonly reported unmet psychological and support treatment needs include obtaining information about cancer, emotional and psychological support services, and practical support services (Zebrack et al., 2013; D’Agostino et al., 2011). The literature suggests that despite a need for specialized services, the AYA population still largely suffers from unmet medical and most notably psychological and support services (Zebrack et al., 2013). These unmet needs may cause undo psychological distress for the AYA population, and for a population already at risk for increased levels of psychosocial difficulties, these unmet needs may impair the emotional functioning of these individuals.

Developmentally, the AYA population is in transition between two critical life periods, childhood into adolescence and adolescence into adulthood. These transitions create many unique psychological challenges. The treatment literature has begun to recognize the benefits of developmentally appropriate medical and mental health practices that focus on allowing the AYA population to live as normally as possible and to participate in early life milestones (Morgan et al., 2010). During adolescence and young adulthood, peer acceptance, appearance, independence and future planning are all important developmental processes affected by the diagnosis of cancer (Lewis, 1996). Additionally, some young adults and adolescents may experience increased levels of depression and anxiety in relation to their sexual desire and functioning (Zebrack, 2011). Psychological treatment therefore is likely an important need of this population in order to cope emotionally with the many physical and emotional side effects of cancer treatment.

Side effects of cancer treatment often lead to changes in an individual's appearance, affecting self-esteem and identity at a time when self-image is developmentally important (Lewis, 1996; Roberts et al., 1998; Evan et al., 2006). Hair loss, weight gain, scarring, and other physical changes impact the AYA population (Lewis, 1996; Albritton, & Bleyer, 2003), and many of these changes are sources of embarrassment and decrease feelings of normality (Evan et al., 2006). According to a study by Bellizzi et al. (2012), 59-62% of AYA participants reported negative impact on their body image, with the greatest impact seen in individuals ages 15-20 years old. Self-esteem and body image issues have grave impact on AYA patients’ medical treatment, and extreme changes in one’s appearance including disfiguring treatments may contribute to medical non-compliance issues (Spinetta et al., 2002). Psychological treatment could be useful for addressing image issues experienced by this population.

There are many invasive side effects of cancer treatment that have negative psychological effects on the AYA cancer population. Cancer treatment may negatively affect an individual’s fertility and ultimately influence developing sexual identity and future planning (Lewis, 1996). Developmentally, sexuality, reproduction, and intimacy are a focus of adolescence and young adulthood, yet many in the AYA population feel negatively about their appearance, have lost interest and ability to have sexual relations, and may be infertile (Epelman, 2013). Not only are there immediate effects on fertility but also life-long future changes that the AYA population faces.

Fertility needs differ by patient’s age and gender. Younger patients were more likely to identify a need for fertility services (Zebrack et al., 2007) whereas older individuals were more likely to want information regarding infertility and options for having children (Zebrack, 2009). Overall, females were more likely to report an unmet need for counseling related to fertility issues (Zebrack et al., 2013). Future family planning and making informed decisions about fertility preservation are important aspects of AYA treatment (D’Agostino et al., 2011). Mental health professionals should also be aware of the impact fertility and sexuality concerns have on the individual’s romantic relationships. Research suggests that AYA cancer patients experience increased levels of pessimism about their future romantic relationships and are fearful of rejection when considering disclosing their cancer history to potential romantic partners (Zebrack, 2011). AYA cancer patients report that uncertainty of fertility is associated with tension in their long term relationships, rejection by a partner, more frequent unprotected sexual practices, and active attempts to conceive a child in order to “feel normal” (Zebrack et al., 2004). The AYA population expresses need and desire to work with mental health professionals in order to develop a safe environment for discussing and processing fertility and sexuality concerns.

Among other psychosocial concerns, peer acceptance is developmentally important for the adolescent and young adult population. However, peer acceptance may be challenged by lack of peer interactions, difficulty disclosing health information to peers (Zebrack, 2011; Lewis, 1996), and difficulty fitting in with peers (Nightingale et al., 2011). Peer relationships are important to the psychological well being of the AYA population as positive peer relationships allow the individuals to retain a sense of normalcy (D’Agostino et al., 2011), and peer support often helps these individuals cope with their cancer (D’Agostino et al., 2011; Zebrack, 2011). Patients commonly report having an unmet need for information that can be provided to friends and peers about their illness (Ishibashi, 2001). Literature suggests that AYA patients have difficulties creating and maintaining social relationships due to social stigma, including being teased because of one’s baldness or being treated as an outcast (Roberts et al., 1998). Adolescents and young adults should be encouraged to maintain normal schedules and engagement in school and work in order to help maintain normalcy and feel socially accepted by healthy peers (Epelman, 2013). Furthermore, increased levels of social support (Albritton & Bleyer, 2003) and involvement in age appropriate social activities may decrease potential issues with treatment non-compliance (Butow et al., 2010). In order to encourage proper psychological adjustment, increased coping skills and decreased medical non-compliance issues, positive peer relationships should be considered as an area of psychological focus in AYA comprehensive programs.

During adolescence and young adulthood, individuals are in a stage of development in which they are seeking greater levels of independence. It is important that a treatment program provides an environment that fosters this independence and encourages this developmentally appropriate expression. Due to their cancer diagnosis, while AYA individuals are seeking independence, they may also experience a high level of dependence on adults or others for medical support (Smith, Davies, Wright, Chapman, & Whiteson, 2007; Roberts et al., 1998). The AYA population may experience lack of independence due to reliance on others for financial support (Lewis, 1996) or the loss of a job due to the cancer (Baker et al., 1993). An adolescent or young adult with cancer may assert independence during treatment in ways that may appear uncooperative or destructive to their care (e.g., refusing treatment) (Robert et al., 1998). However, setting up an environment in which the patient is involved in treatment decision-making helps to promote medical compliance (Spinetta et al., 2002). It is also important in treatment to promote independence in this population as it encourages individuals to stay active in their medical care and better cope with any treatment-related side effects (Williams, 2013). Independence needs vary by age and gender. In a study by Zebrack et al. (2007), older individuals within the AYA population desired to assume responsibility for their own health care, as did males, and the older individuals also preferred greater decision-making capacity for their care. Younger AYA patients expressed that their independence needs included a greater desire for flexible treatment scheduling to avoid missing lifetime milestones (Zebrack et al., 2007). Comprehensive AYA treatment programs may be able to foster developmentally-appropriate independence, including the ability to take greater personal responsibility for one's medical treatment.

In the context of these varied psychological challenges, research suggests that many AYA survivors report a desire to access psychological services (Zebrack et al., 2007; Zebrack, 2009; Zebrack et al., 2013; Zebrack et al.,, 2009). Approximately 30% of adolescents and young adults with cancer however have unmet mental health needs (Keegan et al., 2012). Between 25-50% of the AYA population express needs for counseling and guidance related to sexuality and intimacy, family counseling and spiritual counseling (Zebrack, 2009). However, psychological needs differ by gender and treatment state. Females report greater needs for access to psychological services than their male counterparts (Zebrack et al., 2007), while males were more likely to report an unmet need for spiritual counseling (Zebrack et al., 2013). Individuals who completed medical treatment for their cancer reported a higher need for psychological services than those who were still undergoing medical treatment (Zebrack, et al., 2007). In general, AYA patients who reported a larger number of treatment-related symptoms (shortness of breath, memory or concentration problems, stomach or chest pain, weight loss, frequent fevers, tiredness or fatigue, and frequent headaches) also reported a greater unmet need for mental health counseling (Zebrack et al., 2013). Treatment related to fear of recurrence appeared to be an important psychosocial need for the AYA population. According to a study by Keegan et al. (2012), 50% of the AYA population has unmet information needs about handling fear of recurrence and side effects of long term cancer treatments. Psychological needs are clear but vary among patients depending on age, gender, stage of development, and treatment state. Treatment programs should be sensitive to these differences in psychological needs and provide flexible guidelines to address the most important unmet needs of the AYA population. Despite differences among individuals within the AYA population, a common thread among these individuals is a need for psychological services. With proper access to psychological treatment that is tailored to the diverse needs of the population, it is likely these unmet needs can be fulfilled by comprehensive cancer treatment models.

Information Needs

The AYA population desires a variety of information related to their illness, treatment, long-term effects, guidance about exercise and diet/nutrition, health insurance, disability and social security, mental health and alternative health services, and information about fertility (Zebrack, 2009). In a study by Zebrack (2009), 9.1% of the individuals reported an unmet need for this information. Overall, the literature is consistent in identifying information as an unmet need of the adolescent and young adult population (Zebrack et al., 2013; Keegan et al., 2012; Miedema, Easley, & Robinson, 2013; Smith et al., 2007; Zebrack et al., 2007; Dyson et al., 2012; Hall et al., 2012). Individuals within the AYA population have noted that age-appropriate information is an important need (Zebrack et al., 2007; Miedema et al., 2013; Zebrack, 2009) and this population reports that much of the information they have received is aimed at older or younger individuals with cancer (Smith et al., 2007). Without age-appropriate cancer-related information, patients may have a poorer understanding of their illness and lack important information regarding proper medical care, all of which could lead to problems with treatment compliance (Albritton & Bleyer, 2003). Therefore, information availability may be important to both the medical and psychosocial care of the AYA cancer population.

The AYA population's unmet information needs varies among patient demographics. In one study, unmarried, unemployed, those without a college education, nonwhite, and female were more likely to report an unmet need for information (Zebrack, 2009). Individuals between the ages of 20-39 years old are more likely to report having unmet needs for both cancer-related information and age-appropriate internet-based resources, while patients between the ages of 20-29 years old are more likely to have unmet information needs related to infertility, cancer, and diet/nutrition (Zebrack et al., 2013). Understanding the differences in unmet needs among patient demographics may help professionals target the portion of the AYA population with the greatest need for resources. Providing information regarding cancer treatment, health services, and practical services will allow the patient to gain more independence from others and make well-informed treatment decisions.

Not only is receiving information important to the AYA population, but how that information is presented also holds clinical relevance. In a qualitative study, patients report that information presented in a cold, aloof, patronizing and negative manner made it difficult for AYA patients to make critical treatment decisions (Zebrack, Chesler, & Kaplan, 2010). Many survivors report that providers can make them feel both overburdened with responsibility and dehumanized (Zebrack et al., 2010). Positive communications that instill a sense of hope and help AYA patients better understand their illness, future, cancer experience, and identity are more desired by this population (Zebrack et al., 2010). Overall, poor communication of cancer-related information may increase illness uncertainty and anxiety for patients of the AYA population (Smith et al., 2007). Comprehensive treatment programs may be able to better address the lack of age-appropriate cancer-related information and teach appropriate forms of information communication to both medical and mental health professionals. Better addressing patients' informational needs could, in turn, positively impact well-being and quality of life for AYA survivors.

Support Needs

Adolescents and young adults with cancer desire both social support needs and practical support needs. The AYA population with cancer strives for connections with peers who share a cancer diagnosis. Finding support within the AYA community is important, as research suggests that contact with other individuals with cancer improves psychological well-being and can help individuals cope with psychological challenges (Zebrack, 2011; Baker et al., 1993). AYA individuals gain a sense of community by engaging in activities with other AYA patients, and this support can establish a sense of acceptance and normalcy (Smith et al., 2007). Despite the population's desire to meet others with cancer, current opportunities for connecting with fellow survivors may be limited (Kent et al., 2013). According to a study by Kent et al. (2013), individuals between the ages of 20-29 years old are most likely to report a greater need for meeting other peers with cancer than those of other ages between 15-39 years old. Information about contacting others suffering from cancer is in greater need among the AYA population when familial, romantic, and healthy peer relationships are impacted by the individual’s cancer (Kent et al., 2013). The AYA population expresses a need for multiple different ways to acquire support from others with cancer including internet-based age-appropriate websites (Zebrack et al., 2009), as well as camp programs, workshops and retreats (Zebrack et al., 2009; Zebrack, 2009). Needs for camp programs and retreats are reported as unmet in 50-63% of the AYA population (Zebrack et al., 2009; Zebrack, 2009), and Zebrack (2009) highlights a desire for cancer education and age-appropriate support delivery in such programs. Individuals between the ages of 20-39 are most likely to report unmet needs for age-appropriate camps and retreats offering cancer education and support when compared to individuals ranging in age from 14-39 years old (Zebrack et al., 2013). Emotional support from others in the AYA population not only improves the well being of AYA individuals but helps foster a sense of community and improves coping skills. Integrating programs that encourage AYA patient connections may have positive outcomes on medical and psychological treatment and therefore is important to include in a comprehensive treatment program.

Access to practical support needs is also important for AYA individuals. The AYA population identifies significant needs for assistance in accessing health insurance, child care, transportation services, and knowledge of alternative health care treatments (Zebrack et al., 2013). A greater need for assistance with health insurance occurred for young adults between the ages of 30-39 years old (Zebrack et al., 2013). In one study, 59% of participants reported that having adequate health insurance was their most important unmet need (Zebrack et al., 2007). Young adults treated in the adult settings are more likely than teens in the pediatric setting to report unmet needs for transportation services likely due to their increased family independence (Zebrack et al., 2013). Practical support services are important for clinicians to recognize as they pose barriers to both medical and psychological treatments. Integration of practical support services within comprehensive healthcare programs may allow more psychological, informational, medical, and support needs to be acquired by this population.

Population Heterogeneity

Guidelines for AYAO treatment are limited in the literature and vary by AYA definition, treatment setting, and organization. The heterogeneity of this population poses a unique challenge for researchers, clinicians and program developers, as it is difficult to encompass the vast number and quality of medical and psychological presentations (Geiger & Castellino, 2011). An article by Treadgold & Kuperberg (2010), suggests that although biological presentation of AYA cancer is similar among this population, personal experiences of these individuals are likely to be varied. Furthermore, the article by Treadgold & Kuperberg (2010), suggests that there are notable differences within the AYA population and it should be taken into consideration that “a 15-year-old patient who is attending school and living at home with his or her parents at time of diagnosis will, in many ways, seem to have little in common with a 35-year-old patient who may be married, have been in a career for a number of years, and even be a parent” (p. 4843). Younger AYA individuals are concerned with driver’s licenses, independence, graduating from school, seeking employment and gaining legal independence while others in their 20s and 30s are planning families and careers and settling into intimate relationships (U.S. Department of Health and Human Services et al., 2006). Despite the lack of literature focused on the heterogeneity of the Adolescent and Young Adult cancer population, the acknowledgement of these differences is important to creating developmentally appropriate treatment guidelines that the research heavily emphasizes.

Although literature is slowly beginning to examine the heterogeneity within the Adolescent and Young Adult cancer population, international organizations and treatment centers further add to the challenges for research, guidelines development, and even treatment due to the lack of accepting a universal AYA definition. In the United States, the definition of the AYA oncology population is the most inclusive, ranging from 15-39 years old (NCI, 2013). However, in Australia this age margin is smaller, ranging from 15-29 years old (Australian Institute of Health and Welfare, 2011) and even further reduced in the United Kingdom where the AYA population only consists of patients ages 15-24 years old (Cancer Research UK, 2013). Not only does the definition of an AYA individual vary internationally, within the United States definitions applied to this population vary depending on the facility where treatment is taking place. Medical treatment facilities range from 15-21 years old (Children’s Hospital of Pittsburgh of UPMC, n.d.), 15-30 years old (Seattle Children’s Hospital, 2015), and 15-39 years old (Roswell Park Cancer Center, n.d.; Keck Medical Center of USC, USC Norris Comprehensive Cancer Center, USC Norris Cancer Hospital, & USC University of Southern California, n.d.). The age disparities in international and national AYA population definitions allude to current barriers to treatment development, future research (Geiger & Castellino, 2011) and universal guideline creation.

During the span of life between 15-39 however, it appears there are many different developmental and life transitions that require a further narrowing of this current definition. Literature suggests that with a narrowed defined age range, the entire group of AYA individuals can be compared to narrowed age ranges, exploring when the entire AYA population can be considered together or when certain age ranges are greater affected than others (Geiger & Castellino, 2011). Currently, although literature alludes to differences among those within this age range, research has yet to identify within group differences that could further illuminate how to properly provide care for individuals within the AYA population.

Overall, the heterogeneity of AYA definitions and research outcomes make it difficult to create universal guidelines representing the needs of this population because it is difficult to estimate the needs of the whole population when it is so loosely defined in research. Current literature does not define the AYA population by universal standards and therefore both research and treatment guidelines are written for populations of various age ranges and developmental stages. Most guidelines are similarly composed of treatment strategies for psychosocial issues unique to this population, and many cite the need for developmental and age appropriate treatments (U.S. Department of Health and Human Services et al., 2006; Vanderbilt University Medical Center, 2013; Palmer & Thomas, 2008). In a study by Ferrari et. al (2010), a key theme for developing an AYA oncology program is determining a better definition for which patients constitute the AYA population being treated at the facility, therefore allowing for more appropriate services to be offered. Not only are patients' medical needs different among the AYA population depending on the patients' age, but differences are also apparent in cancer diagnosis, treatment and psychosocial needs (Ferrari et al., 2010). With these differences occurring within the AYA population, current guidelines for the treatment of the unique psychosocial needs may be incomplete or insensitive to developmental changes. Therefore, if adhering to the NCI standards for age range, it is proposed that AYA treatment programs adopt psychosocial treatment models based on developmental and age-based differences. By merging developmental stage theories with current guidelines for psychosocial treatment of the AYA oncology population, psychosocial treatments would be better able to target age specific and developmental specific needs of this population.

CHAPTER 5

CURRENT TREATMENT GUIDELINES

Based on the literature reviewed, the AYA population has many psychological treatment needs that should be integrated into the overall care of AYA individuals. A few treatment guidelines have been proposed for the medical and psychological treatment of the AYA oncology population, but these are lacking guidelines on how to directly address the expressed needs of this population. Guidelines in literature vary from recommendations to treatment protocols however, most guidelines are limited and although developmentally aware, do not fully integrate developmental changes. Important aspects of current guidelines outline ways to increase the AYA population's available information, engagement in treatment both medical and psychological, as well as increase the population's participation in further research.

Current guidelines suggest that overall, AYA youth should be treated by professionals with specialized training and patient understanding. Medical providers should be trained with medical knowledge specific to the AYA population including epidemiology, biology differences, treatment regimens, psychosocial and developmental uniqueness, fertility preservation knowledge, and knowledge of research (Hayes-Lattin et al., 2010). Information delivery is important in the treatment of the AYA population. Information about cancer treatment, side effects and self care are specified needs of the AYA population. Effective methods for providing this information include face-to-face contact with the health care team and age-appropriate brochures, videotapes and DVDs (D'Agostino et al., 2011). Communication of information is important for treatment and increased functioning. Communication increases psychological functioning for this population as well as increased care satisfaction however, communication should be tailored to the specific needs of the AYA population (Gibson et al., 2012). By increasing the knowledge of healthcare providers and communication between providers and AYA patients, this population is likely to benefit from a greater understanding of their treatment and treatment outcomes.

Maintaining normalcy should be integrated into treatment guidelines of the AYA population in multiple ways. Flexibility in treatment ensures that AYA patients are not missing lifetime events, maintaining a sense of normalcy for the patient (D'Agostino et al., 2011; National Comprehensive Cancer Network, 2012). Notable life events for this population include school dances, graduation ceremonies, birthdays and other important social events (D'Agostino et al., 2011). Social relationships are also important for psychosocial functioning, as well as maintaining a sense of normal development. In hospitalized inpatient treatment, patients should be given the opportunity to spend time with friends in an environment that allows patients to socialize as they would normally (e.g., watch a movie or listen to music) (D'Agostino et al., 2011). During psychological treatment, discord in relationships should be addressed and attention paid to decreasing separation from friends and the loss of friendships (D'Agostino et al., 2011) therefore maintaining relationships with their healthy peers (National Comprehensive Cancer Network, 2012) and increasing healthy coping processes (Ettinger & Heiney, 1993). Fostering relationships among AYA individuals is also important (NCCN, 2012) and desired among this population (Kent et al., 2013), further helping to normalize the illness experience as well as foster an environment in which patients can discuss their illness and provide each other support (D'Agostino et al., 2011; Smith et al., 2007). In order to create these relationships, patients should be given a chance to participate in support groups and given a space to socialize with peers in and outside of the hospital environment. Beyond this, creating workshops, programs, camps and retreats for patients to gain education and support from other AYA individuals should be integrated into their care (Zebrack, 2009). Many AYA individuals turn to social media sites to connect with others since lack of age-specific groups in traditional settings fail to meet the needs of this population (Kiem-Malpass & Steeves, 2012). Therefore, group therapeutic intervention and support groups with the AYA population may also be an important tool for the integration of social support and psychological treatment, while online age-appropriate support should continue to be encouraged.

Fertility and sexuality concerns are topics that follow patients throughout their medical treatment and well into survivorship. Fertility issues should be approached prior to treatment so informed decisions may be made regarding options of fertility preservation (D’Agostino et al., 2011). Discussions regarding sexuality and intimacy should be addressed so patients have a better understanding of body image challenges, and changes to their sexual functioning (D’Agostino et al., 2011). Romantic relationships may also be affected so opportunity to engage in couples or family therapy may help to cope with fertility and future family planning.

Planning for the future is often difficult for the AYA population. Delays may occur in education, employment or career goals, and patients should be given proper education and counseling to encourage future planning (D’Agostino et al., 2011). Patients should be encouraged to re-enter educational settings and helped to cope with the transitions into college and the workforce (D’Agostino et al., 2011). Reintegration into school or work helps to promote self-esteem, sustain normalcy and increase coping skills (D'Agostino et al., 2011) therefore it should be a focus of comprehensive treatment.

When looking ahead at the future, the AYA oncology population is also faced with end of life challenges and decisions. Interestingly, only few guidelines look at end of life care (National Comprehensive Cancer Network, 2013a; NCCN, 2012). Within these guidelines, advanced care planning is highlighted (NCCN, 2013a; NCCN, 2012), minimal psychosocial issues are addressed for clinicians (NCCN, 2012) and hospice care is outlined and defined for patients themselves (NCCN, 2013a). It is noted that the AYA oncology youth prefer end-of-life care to occur at home (Palmer & Thomas, 2008; NCCN, 2012) and this aspect of care should be considered when creating guidelines specific to the individual needs of the AYA oncology population. The National Comprehensive Cancer Network (2012) directs clinicians to general oncology palliative care guidelines for both palliative and hospice care concerns. However, these guidelines do not individuate AYA oncology concerns. With limited care guidelines integrating end-of-life care, it appears that guidelines are increasingly focused of improving quality of life and less concerned with quality of death.

Minimally integrated into current guidelines is palliative medicine. Of the guidelines available, only a few offer a section devoted to palliative care (NCCN, 2012; NCCN, 2013a; Palmer & Thomas, 2008). These guidelines highlight the importance of palliative medicine and its role in psychosocial and emotional care (NCCN, 2012; Palmer & Thomas, 2008). Guidelines suggest palliative medicine be introduced early on in the treatment process (NCCN, 2012; NCCN, 2013a; Palmer & Thomas, 2008) and be integrated into primary forms of health care (Palmer & Thomas, 2008). Despite the need for AYA oncology specific treatment suggestions, guidelines are often generalized. The National Comprehensive Cancer Network Clinical Practice Guidelines in Oncology: Adolescent and Young Adult Oncology (2012) for example provide minimal insight into the specific palliative care needs of the AYA oncology population and directs clinicians to the generalized NCCN Guidelines for Palliative Care (National Comprehensive Cancer Network, 2013b). Despite the limited availability of guidelines in AYA palliative care, palliative care is important for the holistic care of the AYA population.

Current Comprehensive Treatment Structure

Current comprehensive treatment guidelines aimed at the integrated treatment of the AYA patient population are limited (National Comprehensive Cancer Network, 2012; Fernandez et al., 2011; Ferrari et al., 2010). Guidelines suggest a multidisciplinary approach and highlight medical and psychological treatment issues including special need training needed for physicians and information addressing the unique psychosocial aspects in-patient care (NCCN, 2012; Fernandez et al., 2011). However, only one study briefly describes guidelines for creating a multidisciplinary AYA population specific treatment center (Ferrari et al., 2010) and despite the growing number of AYA treatment clinics and programs, it seems there is a gap in the current literature in providing comprehensive structural guidelines for AYA specific clinics.

Treatment at Other Institutions

In comparison, multiple Adolescent and Young Adult treatment programs across the United States are designed with similar components in mind. Across treatment programs, medical and psychosocial issues are often treated in conjunction. Medical services include specific cancer treatments, fertility support and treatment (Keck Medical Center of USC et al., n.d.; Robert H. Lurie Comprehensive Cancer Center of Northwestern University, n.d.; Oregon Health and Science University, 2015; The University of Texas MD Anderson Cancer Center, 2015; Children's Hospital of Pittsburgh of UPMC, n.d.), and a specialized focus on survivorship care (Keck Medical Center of USC et al., n.d.; Robert H. Lurie Comprehensive Cancer Center of Northwestern University, n.d.; Children's Hospital of Pittsburgh of UPMC, n.d.). Most programs focus on psychosocial concerns for this population by providing general psychological services (Children's Hospital of Orange County, 2014; Keck Medical Center of USC et al., n.d.; Robert H. Lurie Comprehensive Cancer Center of Northwestern University, n.d.; The University of Texas MD Anderson Cancer Center, 2015; Children's Hospital of Pittsburgh of UPMC, n.d.), as well as psychoeducation and information regarding cancer and cancer resources (Children's Hospital of Orange County, 2014; Keck Medical Center of USC et al., n.d.; Robert H. Lurie Comprehensive Cancer Center of Northwestern University, n.d.; Children's Hospital of Pittsburgh of UPMC, n.d.). Many programs also offer practical support services including health insurance resources (Robert H. Lurie Comprehensive Cancer Center of Northwestern University, n.d.), financial information (Robert H. Lurie Comprehensive Cancer Center of Northwestern University, n.d.; Keck Medical Center of USC et al., n.d.; Children's Hospital of Pittsburgh of UPMC, n.d.), and educational resources (Keck Medical Center of USC et al., N.D.; Robert H. Lurie Comprehensive Cancer Center of Northwestern University, n.d.; The University of Texas MD Anderson Cancer Center, 2015; Children's

Hospital of Pittsburgh of UPMC, n.d.). In order to foster connection between youth, many AYA programs offer camps (Oregon Health and Science University, 2015), and communal social activities for AYA youth, as well as a physical space devoted just to the AYA oncology population (Children's Hospital of Orange County, 2014; Robert H. Lurie Comprehensive Cancer Center of Northwestern University, n.d.; The University of Texas MD Anderson Cancer Center, 2015; Children's Hospital of Pittsburgh of UPMC, n.d.). One of the most important aspects to a treatment programs includes access to clinical trials and research information. Programs may offer on site research as well as partnerships with other research organizations in order to increase this population's engagement in clinical trials regarding their treatment (Children's Hospital of Orange County, 2014; Keck Medical Center of USC et al., n.d.; Robert H. Lurie Comprehensive Cancer Center of Northwestern University, n.d.; Oregon Health and Science University, 2015; Children's Hospital of Pittsburgh of UPMC, n.d.). Looking across programs, AYA oncology treatment highlights the specific needs of the AYA population and offers different ways to effectively target these challenges.

There are limited but increasing numbers of AYA treatment programs and clinics implemented in the United States and abroad for comprehensive treatment of the AYA population. Many AYA programs offer similar services however some have addressed the specific challenges of this population in unique ways. An example of a comprehensive program addressing the unique needs of the AYA population is The University of Texas MD Anderson Cancer Center, Children's Cancer Hospital AYA Program. The University of Texas MD Anderson Cancer Center combines medical and psychological treatment in order to provide comprehensive treatment to the AYA population. Medically, this program offers medical treatments that help to preserve the youth's normal functioning and appearance (The University of Texas MD Anderson Cancer Center, 2015) an important aspect of helping preserve a sense of normalcy in this population. The University of Texas MD Anderson Cancer Center, meets the sexuality and fertility needs of this population by offering fertility clinic services consulting with AYA youth on infertility risks, fertility preservation options, as well as potential studies investigating fertility issues among this population (Farris, 2011). Medically, this program offers the latest cancer treatments and access to AYA medical specialists (The University of Texas MD Anderson Cancer Center, 2015). Not only does this program offer specialized medical treatment for the AYA population but also attempts to meet a great number of the psychosocial needs of this population as well.

Normalcy is a highlight of this program, offering the AYA population opportunities to obtain typical adolescent and young adult experiences. Education is an important part of the AYA population's functioning. A unique way this program supports educational experiences is it offers a private school for youth treated within the hospital (The University of Texas MD Anderson Cancer Center, 2015). The school focuses on providing education, school re-entry services for the youth, and opportunities to engage in educational field trips (The University of Texas MD Anderson Cancer Center, 2015), further decreasing the youth's detachment from normal AYA school experiences. Not only does The University of Texas MD Anderson Cancer Center offer educational experiences but also provides career and vocational counseling. Another specialized aspect of this program is its understanding and targeting of heterogeneity within the AYA oncology population. Valuing developmental differences, the program provides different support services to individual in high school, college and those within the workforce (The University of Texas MD Anderson Cancer Center, 2015). High school students can obtain counseling regarding college preparatory exams, financial aid, and college applications whereas workforce counseling provides guidance regarding career exploration, job interview skills, and resume writing (The University of Texas MD Anderson Cancer Center, 2015). A particular strength of this program is providing services to the AYA population based on developmental differences and developmental needs.

Increasing experiences in which AYA youth interact with other AYA individuals is an identified need for this population (Kent et al., 2013). The University of Texas MD Anderson Cancer Center offers multiple ways for the AYA population to interact and provide support to one another. The program offers a young adult support group as well as multiple forms of developmentally appropriate AYA oncology youth gatherings (The University of Texas MD Anderson Cancer Center, 2015) again, being mindful of the heterogeneity within this population. A free camp is offered to adolescent youth ages 13-18 years old providing experiences to increase the youths' independence while also providing an environment that fosters relationships with similar oncology youth (The University of Texas MD Anderson Cancer Center, 2015). For youth ages 15-30 years old, The University of Texas MD Anderson Cancer Center offers a social environment called Kim's Place (The University of Texas MD Anderson Cancer Center, 2015). Kim's place offers AYA social hours and age appropriate social activities including a movie theater, pool table, video games, and basketball free throw machines (The University of Texas MD Anderson Cancer Center, 2015). Cancer180 is another program offered by The

University of Texas MD Anderson Cancer Center. Cancer180 is a program for AYA youth in their 20s and 30s providing social events, outing and activities in order to foster relationships between AYA individuals (The University of Texas MD Anderson Cancer Center, 2015). By providing developmentally appropriate services for AYA youth this program is able to better focus on the AYA individual's support needs.

In this particular program, psychosocial needs are met through various aspects of the treatment program. The University of Texas MD Anderson Cancer Center offers support groups, psychological counseling, and child life specialists (The University of Texas MD Anderson Cancer Center, 2015). A unique aspect of this program is the Adolescent and Young Adult Advisory Council. The Adolescent and Young Adult Advisory Council is created of 12 AYA individuals and 14 medical professionals who discuss the services offered at the institution and those still needed for AYA patients (Farris, 2011). Through this council, The University of Texas MD Anderson Cancer Center is able to better identify patient needs and individualize their treatment program (The University of Texas MD Anderson Cancer Center, 2015). Overall, The University of Texas MD Anderson Cancer Center is a good example of a multidisciplinary team within a hospital setting that meets the expressed needs of the AYA population.

Another example of a multidisciplinary treatment program based on the unique needs of the AYA population, is the Adolescent and Young Adult (AYA) Oncology Program at Children's Hospital of Pittsburgh. This program utilizes an adolescent medicine specialist approach in which treatment for the AYA population is given through an AYA specialized medical team working closely with oncologists (Children's Hospital of Pittsburgh of UPMC, n.d.). At the Children's Hospital of Pittsburgh, the AYA oncology program offers fertility preservation services for AYA individuals including both experimental and traditional forms of fertility treatments (Children's Hospital of Pittsburgh of UPMC, n.d.). As a patient at the Children's Hospital of Pittsburgh, AYA individuals are offered many chances to engage in outside research projects at the Children's Oncology Group and University of Pittsburgh Cancer Institute (Children's Hospital of Pittsburgh of UPMC, n.d.). Unique aspects of the program include coordination with palliative care and hospice services (Children's Hospital of Pittsburgh of UPMC, n.d.). The program also targets survivorship and values provisions of long-term follow-up care for AYA cancer survivors (Children's Hospital of Pittsburgh of UPMC, n.d.). Survivorship is celebrated with events connecting survivors and the program offers significant information and psychoeducation regarding survivorship on their website (Children's Hospital of Pittsburgh of UPMC, n.d.). Medical services are also provided in conjunction with psychological services to treat AYA youth comprehensively.

There are multiple psychosocial services offered for AYA oncology youth at Children's Hospital of Pittsburgh. Psychological services are offered including psychiatry support and support group services (Children's Hospital of Pittsburgh of UPMC, n.d.). Financial services and workplace support are available to AYA individuals including tutoring services to keep youth up to date on their school studies (Children's Hospital of Pittsburgh of UPMC, n.d.). AYA life specialists help to engage AYA individuals in developmentally appropriate activities including reading, movies and chaperoned community outings (Children's Hospital of Pittsburgh of UPMC, n.d.). To encourage connection between AYA youth, social outings and weekend retreats are offered in this program (Children’s Hospital of Pittsburgh of UPMC, n.d.). The Teen Lounge helps promote normalcy and peer interactions by providing developmentally appropriate activities for AYA youth (Children’s Hospital of Pittsburgh of UPMC, n.d.). Overall, the Children’s Hospital of Pittsburgh provides immense psychoeducation and information through their website. Information is provided in a developmentally appropriate manner including personal videos, and links to resources regarding disease information, clinical trials, online support groups, and fertility are available (Children’s Hospital of Pittsburgh of UPMC, n.d.). Both program examples given depict how services can be provided based off patients’ identified needs and how multidisciplinary teams can integrate medical and psychological treatment in a developmentally appropriate manner.

In January of 2014, the Robert H. Lurie Comprehensive Cancer Center of Northwestern University was designated a center of excellence in AYA oncology by the Health Care Rights Initiative (Robert H. Lurie Comprehensive Cancer Center of Northwestern University, n.d.). In analyzing differences between the aforementioned programs and a recognized treatment program, several important distinctions arose. The Adolescent and Young Adult program at the Robert H. Lurie Cancer Center is the only program reviewed in which a clinical psychologist leads the treatment team and treatment program (Robert H. Lurie Comprehensive Cancer Center of Northwestern University, n.d.), possibly leading to an increased emphasis on psychosocial support services and research needs. The Supportive Oncology Team at the Lurie Cancer Center is impressively made up of six clinical psychologists, six social workers, one psychiatrist, one psychiatric nurse practitioner, and a licensed clinical social worker (Robert H. Lurie Comprehensive Cancer Center of Northwestern University, n.d.). With a support team as large and comprehensive as the one at the Robert H. Lurie Cancer Center it is likely treatment provides an increased focus on psychosocial challenges for this population. Along with psychological support services, nutritional counseling, alternative medical treatments (acupuncture, massage therapy, Reiki), and rehabilitation services are offered on site and through community partner referrals (Northwestern Medicine & Robert H. Lurie Comprehensive Cancer Center of Northwestern University, n.d.). Fertility services and information is not only provided, information is presented in a interactive way allowing individuals to obtain treatment material based on their gender, treatment phase, and developmental stage (Northwestern University, 2011). One of the most notable differences is the program's emphasis on survivorship services. The Robert H. Lurie Comprehensive Cancer Center offers patients in all stages of cancer treatment and recovery the opportunity to participate in services at the Cancer Survivorship Institute (Northwestern Medicine & Robert H. Lurie Comprehensive Cancer Center of Northwestern University, n.d.). The AYA oncology population, through the Survivorship Program, is offered support services including psychological services, nutrition counseling, fertility treatment, financial support, diagnosis specific specialty services, rehabilitation, and alternative medical services (Northwestern Medicine & Robert H. Lurie Comprehensive Cancer Center of Northwestern University, n.d.). Within this program, palliative care is also highlighted in order to help the youth's treatment accurately reflect his or her goals (Northwestern Medicine & Robert H. Lurie Comprehensive Cancer Center of Northwestern University, n.d.). A unique and developmentally appropriate way this program offers information and support is through social media. The Robert H. Lurie Comprehensive Cancer Center of Northwestern

University offers social media connections through Facebook, Youtube, Instagram, and Twitter allowing information to be relayed in an developmentally appropriate manner (Northwestern Medicine & Robert H. Lurie Comprehensive Cancer Center of Northwestern University, n.d.). Overall, this program offers many of the same services as other programs including fertility counseling, access to clinical trials, state of the art medical procedures, and practical support services (Northwestern Medicine & Robert H. Lurie Comprehensive Cancer Center of Northwestern University, n.d.). Combined with extra emphasis in psychosocial support, alternative and holistic support services, developmentally appropriate fertility information regarding treatment, and survivorship care, this program has been seen as a first-rate treatment program.

CHAPTER 6

TREATMENT AT LOMA LINDA UNIVERSITY

Loma Linda University Medical Center and Children’s Hospital provide medical treatments to the greater Los Angeles area and have the opportunity to potentially better serve the AYA population. Currently, cancer treatment specifically focused on the adolescent and young adult population with cancer at Loma Linda University is limited. Although current programs are available for pediatric care and adult services, it is likely that without access to AYA specific treatments, this population has the potential to be better supported both medically and psychologically. The unique needs of this population make specialized treatment a greater necessity, and with limited programs in the Southern California area, many adolescent and young adults with cancer would benefit from a comprehensive treatment program at Loma Linda University.

Currently, there is no specific Adolescent and Young Adult Oncology program at Loma Linda University, neither in the Loma Linda University Children’s Hospital nor within the Loma Linda University Medical Center. Loma Linda University offers many programs for oncology patients and includes an integrative Cancer Center. However, despite the services available, non directly cater to the AYA population. It is suggested that this population is unique in their needs and treatment strategies therefore, to better treat this population Loma Linda University would benefit from establishing a program directed at this population.

Current Strengths of Loma Linda University Cancer Treatment

Loma Linda University Medical Center offers many treatment options for cancer patients. One of the biggest strengths of the programs offered at Loma Linda University is the Loma Linda Cancer Center. Despite the lack of options specific to the AYA oncology population, the Loma Linda Cancer Center is a multidisciplinary program facility offering medical oncology treatment with a handful of psychosocial support services (Loma Linda University Medical Center, 2015). According to their website, treatment at the Loma Linda Cancer Center treatment is vast, covering treatment for pediatric, breast, gastroenterology, neurological, skin and pediatric cancers (Loma Linda University Medical Center, 2015). Among state of the art treatments, the Loma Linda Cancer Center boasts its minimally invasive surgery techniques, advanced imaging capabilities, proton therapy treatment, cancer research, and extensive cancer resources (Loma Linda University Medical Center, 2015). The Cancer Resource Center, a division of the Cancer Center, provides two support groups for their patients (Women’s General Cancer and Men’s Prostate Cancer), some degree of psychosocial support, and multiple ways to increase the oncology patients’ knowledge of their illness and treatment (Loma Linda University Medical Center, 2015). Integrated within primary healthcare, patients have access to palliative care and pain management services with a focus on the adult and pediatric populations (Loma Linda University Medical Center, 2015). Information is highly important to the AYA oncology population and despite lack of information specifically aimed at the AYA oncology population, the Cancer Center and Loma Linda Children’s Hospital have extensive platforms to increase access to information for those with cancer diagnoses.

Information needs are well met for adolescent and adult populations at Loma Linda Medical Center and Loma Linda Children's Hospital. On the Loma Linda Children's Hospital website, the Teens Cancer Center offers increased information regarding many aspects of adolescence and cancers effects on normal life events (Loma Linda University Medical Center, 2008). Information can be found surrounding definitions of different types of cancer, treatments and cancer prevention, psycho-social effects of cancer, and personal stories of other youth experiencing cancer diagnosis and treatment (Loma Linda University Medical Center, 2008). Presented in a relatively developmentally appropriate manner, the information is broken down into easy to learn information and contains pictures, videos and even questions adolescents can ask of their healthcare providers (Loma Linda University Medical Center, 2008). Created in 2008, this information is in need of update and an increase in articles based on the needs of the adolescent population however, it is a good framework for adapting a similar website for the AYA oncology population. Similarly, the Loma Linda Cancer Center website offers a health library with information for oncology patients. There is a wealth of information presented on the Loma Linda Cancer Center website including information regarding basic cancer facts, cancer treatment and procedures, side effects, psycho-social issues in relation to cancer diagnosis and treatment, and discussion surrounding ways to improve quality of life and emotional functioning (Loma Linda University Medical Center, 2015). Geared towards independent adults, information presented on the Cancer Center website often concludes adults reading the information are employed, financially independent, have families, are caring for children with cancer, and have children and significant others of their own (Loma Linda University Medical Center, 2015). This vast array of information is likely extremely beneficial to individuals diagnosed in middle to late adulthood however, information is not developmentally appropriate for young adults suffering from cancer. Like the website dedicated to adolescents from the Loma Linda Children's Hospital, the information provided on the Cancer Center website provides a solid foundation for increasing informational needs of the AYA population.

Within the Loma Linda University Medical Center, there are a few options to provide support services to the oncology population. A strength of the Cancer Center is its attempt to integrate psychological and supportive services into the primary care of its oncology population. However, it appears access and abundance of psychosocial support is limited. Support groups are offered weekly for men and women as well as alternative therapy aimed to increase healing through therapeutic movement to music (Loma Linda University Medical Center, 2015). Social workers and a psychology intern are also available to help patients manage emotional and psychosocial issues (Loma Linda University Medical Center, 2015). Resources for patients are offered in the form of patient navigators who provide education, support, and advocacy for patients in developing individualized approaches to treatment and referring patients to supportive services, providing patient education, and addressing an individual's barriers to treatment (Loma Linda University Medical Center, 2015). By increasing the provision of emotional support, the Loma Linda University Cancer Center can increase its value and treat the oncology population with a more holistic lens. With improvements in provisions of accessible mental health and support services, the Loma Linda University Medical Center can lay a better foundation to support an AYA oncology integrated treatment program.

CHAPTER 7

RECOMMENDATIONS FOR TREATMENT AT LOMA LINDA UNIVERSITY

Multidisciplinary Adolescent and Young Adult oncology programs are important to providing adequate care and ultimately increasing survival rates of this population. There are many benefits to creating an AYA specific treatment setting however there are several barriers to providing quality of care for this population. Overall, it is recommended that due to the increased population heterogeneity, that guidelines for treatment of the AYA oncology population be based on developmental variation within this population. As more research becomes available, it is recommended that the guidelines be revisited in order to update them with identified developmental differences and specific needs of the population. In working with the current infrastructure at Loma Linda University Medical Center and capitalizing on current program strengths, the following are recommendations for implementing a multidisciplinary AYA oncology treatment program at Loma Linda University. Recommendations followed by an asterisk are guidelines that are strongly encouraged however may be later implemented as the AYA Oncology Program continues to develop at Loma Linda University. It is to be noted that medical treatment and training are beyond the scope of the current dissertation and will not be addressed in the following recommendations.

Recommendation 1: Provide AYA Team Within Loma Linda Cancer Center

The Loma Linda Medical Center currently provides a multidisciplinary setting within the Loma Linda Cancer Center that the adolescent and young adult population would greatly benefit from. It is recommended that the Loma Linda Cancer Center implement:

- A multidisciplinary AYA oncology team should be developed and include medical and mental health professionals. Team members may include: medical professionals from pediatric and/or adult oncology backgrounds and mental health professionals with experience working with the AYA oncology population. Other members may also include: nutritionists, child life specialists, surgeons, school/workplace counselors, case managers, fertility specialists, and palliative medicine professionals.
- The AYA team should have specific training and/or continued education regarding specific AYA medical and psychological needs. An example of continuing education courses includes the Focus Under Forty coursework offered by the American Society of Clinical Oncology (American Society of Clinical Oncology, 2015).
- Professionals within the team should have extensive knowledge of AYA development and its heterogeneity, as well as understanding of a vast array of medical and psychosocial needs (Ferarri et al., 2010).
- The AYA Cancer Program should offer specific trainings, seminars and rounds directed specifically at the AYA oncology population.
- This team will provide inpatient and outpatient services at the Cancer Center and within the Loma Linda Medical Center and Children's Hospital.

Overall, adolescent and young adult care needs are specific and unique addressing the complexities of this population. Since the Loma Linda Cancer Center is already established, a specific AYA treatment team could begin integrating adolescent and young adult care into current treatments offered.

Recommendation 2: Provide an AYA Specific Space

Literature recommends that the adolescent and young adult population be provided with a developmentally appropriate space. Recommendations include:

- An area in the Cancer Center waiting room with AYA specific magazines and books (Ferarri et al., 2010) or may include developmentally appropriate brochures (D'Agostino et al., 2011) and resources.
- This area of the waiting room may provide postings of AYA outings, events, support groups, camps, websites, online support groups, Facebook groups and other resources.
- A common space should be provided to engage in AYA specific activities such and playing video games, listening to music and watching movies with others, hanging out with friends, and access to social medias (D'Agostino et al., 2011). This space should also be devoted to AYA support groups, gathering, and social events that help foster social interactions and normalcy (D'Agostino et al., 2011).

By providing an AYA specific area, this population has the chance to access developmentally appropriate social interactions and continue fostering normalcy.

Recommendation 3: Promote Research

There is a lack of research aimed at the AYA oncology population. The following are recommendations for implementing research into the AYA oncology program:

- Obtain funding for AYA specific research trials.
- Recruit AYA individuals in both outpatient and inpatient settings.
- Conduct long and short-term studies on psychosocial aspects of the AYA population and treatment models successful for treatment in the population.
- Research should be conducted regarding AYA population heterogeneity and within group differences in order to better understand minute aspects of psychological care.
- Conduct program based research to determine areas in which the implemented AYA program requires improvements in striving to meet the population’s needs.
- Better understand barriers to AYA research and develop solutions to research barriers in order to increase research results.

Overall, much is still unknown regarding the AYA population and implementing research based on the AYA treatment program will help to provide better quality of care in treating the AYA population.

Recommendation 4: Provide Developmentally Appropriate Information

Many within the AYA population note that information is of great importance and can be an unmet need for the population (Zebrack et al., 2013; Keegan et al., 2012; Miedema et al., 2013; Smith et al., 2007; Zebrack et al., 2007; Dyson et al., 2012; Hall et al., 2012). Information needs further highlight a desire for information presented in an age appropriate manner (Zebrack et al., 2007; Miedema et al., 2013; Zebrack, 2009). The following are recommendations for providing developmentally appropriate information to the AYA oncology program:

- Improve upon the Loma Linda University Cancer Center website providing AYA targeted information.
- Information should be presented in ways that address the developmental heterogeneity of the population (i.e. talk about both job force and school reintroduction).
- Provide information for the AYA population that increases social awareness or connection (i.e. provide normalcy and understanding by providing stories from other AYA individuals).
- Provide information based on ways to increase the AYA individuals' independence during treatment (i.e. information highlighting the AYA population's choices, expand on Loma Linda University's selection of questions to discuss with their medical providers).
- Create age-appropriate brochures in the following areas: fertility and sexuality, education and workplace, risky behaviors, mental health, body image, practical support, palliative care, support groups, How to talk with family about illness, how to talk with peers about illness etc.
- Information should be available electronically (i.e. a website, an iPhone app*, downloadable pdf).
- Utilize social media to provide resources and information to the AYA population and offer individuals a chance to discuss and connect to share information.

- Provide cancer education programs and venues (i.e. seminars and workshops focused on the AYA population needs) (Zebrack et al., 2009; Zebrack, 2009).

Providing developmentally appropriate information to this population increases the AYA population's knowledge of their treatment and treatment outcomes.

Recommendation 5: Provide Adequate Social Support Between AYA Individuals

The Adolescent and Young Adult Oncology population have unique and important supportive needs. The AYA oncology population desires increased connections with oncology and healthy peers. Providing high levels of social support is crucial to the AYA populations' developmental trajectory (Zebrack, 2011) and psychological well-being (Zebrack, 2011; Baker et al., 1993). The following are recommendations for providing adequate social support for the AYA oncology population:

- Provide support groups for AYA individuals to discuss and obtain support in regards to their difficulties in multiple facets of their cancer diagnosis. Support groups should be based on developmental status of the individuals therefore, increasing their ability to connect with peers going through similar life events.
- In order to increase the AYA population's access to obtain support, an option to provide online support groups allows AYA oncology youth to utilize a familiar platform in order to connect with similar peers.*
- Utilize social media (Facebook, Twitter) to provide a platform for AYA oncology youth to connect with other oncology youth.
- A special focus should be created aimed at recruiting and establishing social support activities for youth ages 20-29 (Kent et al., 2013).

- The AYA oncology population desires increased access to oncology related camps, workshops and retreats (Zebrack et al., 2009; Zebrack, 2009). It is therefore recommended that the AYA oncology program provides information regarding camps, workshops and retreats. *In the future, the program should develop such activities for the AYA population treated at the Loma Linda Cancer Center.
- The AYA oncology youth aged 20-39 years old report increased needs for camps and retreats (Zebrack et al., 2013) therefore, programs at the Loma Linda Cancer Center should be conscious to increase access to these resources within the treatment program.

Providing increased social support between AYA individuals may ultimately increase the population's well-being and treatment outcomes.

Recommendation 6: Provide Access to Practical Support

The following are recommendations to provide AYA individuals with practical support within a Loma Linda AYA Cancer Program:

- Access to health insurance is a significant need for the AYA population most notably with the ages of 30-39 year-olds (Zebrack et al., 2013). The Loma Linda AYA Cancer Program should include workshops on insurance education and health care applications and the AYA Cancer Program team should include case managers to provide practical support in order to help individuals gain access to insurance.

- AYA oncology patients should be provided with information regarding transportation services in the area to help increase access to the Cancer Center facility. *The Loma Linda University Cancer Center AYA program should offer in-home services within the community to AYA individuals unable to access the Cancer Center due to illness related difficulties.
- AYA individuals express a desire to receive knowledge of alternative health care treatments (Zebrack et al., 2013). The AYA Cancer Center Program should continue to offer alternative forms of healing for individuals (i.e. yoga therapy) as well as increased information available to the AYA population regarding alternative health care treatments and resources.

Overall, decreasing the AYA oncology population's barriers to treatment and increasing their knowledge base of available resources will likely increase the populations' access and engagement in treatment.

Recommendation 7: Treatment Flexibility

The following are recommendations to provide developmentally appropriate treatment flexibility for AYA individuals within a Loma Linda AYA Cancer Program:

- The Loma Linda AYA Program should consider the heterogeneity of experiences within the AYA population in regards to medical treatment.
- Due to increased heterogeneity, couples, family, individual, and group therapy options should be available to this population.
- AYA individuals, due to the large span of age inclusion, vary with education and workforce involvement. Normal schedules are encouraged for this population

(Epelman, 2013) therefore, appointment scheduling flexibility should be priority for the AYA individuals. *Appointments should be available after normal work and school hours.

Normalcy is important to the AYA population (D'Agostino et al., 2011) however normal trajectories appear different within this heterogeneous population. To maintain normalcy and address the variety of patient needs, heterogeneity should be highlighted in all aspects of patient care.

Recommendation 8: Palliative Care

This paper does not address extensive palliative care guidelines however, the following are brief recommendations in regards to Palliative Care provisions within a Loma Linda AYA Cancer Program:

- Palliative medicine treatments and teams should be introduced early on in the treatment for AYA individuals (NCCN, 2012; NCCN, 2013a; Palmer & Thomas, 2008).
- Guidelines should be identified for AYA specific palliative care needs. With limited guidelines are available, the AYA Cancer Program should adapt NCCN guidelines to meet the needs of the AYA population while continuing research to identify effective guidelines specific to this population.

Recommendation 9: Risky Behaviors

The following are recommendations to provide treatment regarding risky behaviors within the AYA oncology population:

- Due to the AYA oncology population’s increased susceptibility to medical non-compliance (Suris et al., 2004), platforms providing psychoeducation regarding compliance should be offered for this population. These platforms may be in the form of individual or group therapy, compliance workshops and seminars, or psychoeducation provided directly by the medical providers.
- The AYA oncology treatment team should dedicate increased resources to providing AYA youth with an in depth understanding of their treatment regimens, the seriousness of the youth’s illness (Spinetta et al., 2002) and the importance of compliance.
- The AYA Cancer Program should allocate resources to clinical trails focused on increasing medical adherence to treatment regimens.
- Psychoeducation should be provided regarding risk taking behaviors including substance use and alcohol effects on treatment and prognosis. Multiple platforms of information delivery should be utilized including, individual and group therapy, risky behavior workshops and seminars, and psychoeducation provided directly by the medical providers.
- With an increased susceptibility to sexually transmitted infections (Murphy et al., 2013), youth should be provided in-depth psychoeducation regarding STIs and their effects on this population. Multiple platforms of information delivery should be utilized including, individual and group therapy, risky behavior workshops and seminars, and psychoeducation provided directly by the medical providers.

By providing increased psychoeducation and treatment regarding compliance and risk taking behaviors, the AYA Cancer Program may better target non-compliance and behaviors hindering progression in treatment and treatment outcomes.

Recommendation 10: Psychological Distress

The following are recommendations to provide treatment regarding psychological distress within the AYA oncology population:

- The AYA Cancer Program at Loma Linda University should identify and utilize quick assessments for recognizing distress in the AYA population and their need for psychological services and resources. AYA patients should be assessed for distress at multiple points during treatment.
- The AYA population should be given multiple options to engage in therapy. Increased levels of psychological distress have been seen at the initial cancer diagnosis and after treatment is completed (Jorngarden et al., 2007; Larsson et al., 2010; Kwak et al., 2013) therefore these points are critical for offering services to these individuals.
- Diverse psychological treatment modalities should be available for the AYA population including individual, group and family therapy, and support groups. Psychological services should be encouraged with multiple referral sources from each team member.
- Brochures should be available to the population that increase the AYA population’s knowledge and access to psychological treatment.

- Psychological treatment should be available during both the inpatient and outpatient care of the youth.
- Psychological treatment modalities should be grounded in evidenced based treatment and updated as current research becomes available. *Funding should be provided to conduct research focused on treatment modalities for the AYA population.
- AYA youth report unmet needs for spiritual counseling (Zebrack et al., 2013) therefore spiritual counseling should be a referral option from the AYA cancer team.

Recommendation 11: Body Image

The following are recommendations to provide treatment regarding body image issues for the AYA oncology population:

- Multiple platforms should be dedicated to psychoeducation on bodily changes and body image issues. Bodily changes including those from medication side effects and treatment should be highlighted. Multiple platforms of information delivery should be utilized including, individual and group therapy, body image workshops and seminars, and psychoeducation provided directly by the medical providers.
- Concerns regarding hair loss are important to this population (Ettinger & Heiney, 1993; Roberts et al., 1998; Lewis, 1996; Evan et al., 2006) therefore, hair loss alternatives such as wigs, should be an available resource to the AYA population.
- Support groups and seminars should be available to discuss bodily changes and body image issues.

Recommendation 12: Practical Support

The following are recommendations to provide treatment regarding education and workplace related issues for the AYA oncology population:

- Within the population there is increased heterogeneity in relation to education and workplace issues. AYA individuals may be in high school, college, or in the workplace and issues vary among the population. It should be noted that education and workplace support should be tailored to the individual when offered to this population.
- Treatment should be flexible for this population and should interfere as little as possible with normal functioning. Treatment therefore should be offered at flexible hours that do not conflict with education or workplace responsibilities.
- For AYA individuals in inpatient services, school liaisons and tutors should be available to advocate for the youth's education and movement towards school completion.
- For those looking at entering the workforce or currently in the workforce, career counselors should be made available for guidance and extra support. Career counselors should focus on occupation exploration, an important developmental task for the AYA population (Stern et al., 1991). Career counseling should also include psychoeducation surrounding how to obtain disability and overcoming job discrimination and biases.

- Financial planning is a source of distress for this population therefore it should be built into the program by offering resources in the form of workshops and seminars based in financial awareness.
- Multiple transitions occur in the AYA individual's lifetime surrounding education and the workforce. To increase support regarding these transitions, seminars and workshop should be held and dedicated to college applications, building a resume, job applications etc.

Recommendation 13: Sexuality & Fertility Needs

The following are recommendations to provide treatment regarding sexuality and fertility issues for the AYA oncology population:

- There are increased levels of heterogeneity within the AYA oncology population in regards to fertility issues. When treating the AYA oncology population, the treatment team must be knowledgeable of the population's different developmental needs in order to effectively treat fertility issues.
- Psychoeducation should be provided in regards to fertility issues, treatments and services as well as their changes as the youth develops. The AYA individual should be informed of fertility issues and treatment options early on in their cancer treatment.
- Psychoeducation should continue across the youth's treatment to increase the youth's understand of treatment effects on the youth's fertility. Multiple platforms of information delivery should be utilized including, individual and group

therapy, fertility workshops and seminars, and psychoeducation provided directly by the medical providers.

- Workshops and seminars should be provided surrounding fertility and intimacy difficulties for this population. Support groups should also be available for youth to discuss personal experiences and knowledge of fertility and intimacy struggles.
- Family planning should be offered to the AYA population in order to help individuals make informed decisions about fertility preservation and treatments (D'Agostino et al., 2011).
- In psychological treatment, mental health professionals should focus on fertility and it's relation to peer relationships, romantic and intimate relationships, risky behaviors, and family planning.

Recommendation 14: Family

The following are recommendations to provide treatment regarding family relationships in the AYA oncology population:

- Family therapy should be available to the AYA oncology population. Psychoeducation should be provided for all members of the family about cancer and its effects on family dynamics and family functioning.
- Family support groups should be offered to provide increased support for families of AYA oncology youth. *Different support groups should be offered for parents, spouses, and children of the AYA oncology population. Each family member is likely to have multiple unique role changes and difficulties resulting from a cancer diagnosis.

Recommendation 15: Peers

The following are recommendations to provide treatment regarding peer related issues for the AYA oncology population:

- Peers are developmentally important to the AYA oncology population. Both oncology peers and healthy peers are important to integrate into treatment. Social events should be held for the AYA oncology youth to foster relationships with other youth suffering from cancer and to maintain relationships with their healthy peers. Social events can include movie nights, dances, game nights, and other developmentally appropriate events.
- Seminars should be held on how to talk with friends about cancer and brochures should be available detailing different ways to begin a conversation with friends about diagnosis and treatment. Developmentally appropriate presentation of the material is important including brochures available with age and developmental considerations.
- For AYA oncology youth, opportunities should be given to develop and practice interpersonal skills. Social hours and/or social groups should be offered to allow for closer personal connections with other AYA individuals.
- Family nights should be held for AYA individuals and their children to increase socialization and support.

CHAPTER 8

SUMMARY

Based on the literature reviewed, the AYA population has many psychological treatment desires that should be integrated into the overall care of AYA individuals. Although current programs are available for pediatric care and adult services, it is likely that without access to AYA specific treatments, this population is being underserved and has the potential to be better supported both medically and psychologically. AYA oncology specific programs are likely to better address the needs of this population and holistically treat an individual hopefully increasing survival and positive outcomes for this population. The unique needs of this population make specialized treatment a greater necessity and with limited programs in the Southern California area, many adolescent and young adults with cancer would benefit from a comprehensive treatment program at Loma Linda University. The Loma Linda Cancer Center has many strengths and by capitalizing on these strengths and providing specific programs to address AYA needs, Loma Linda University would be able to implement improvements in their comprehensive treatment of the AYA population. Overall, AYA specific programs are essential to moving forward with the treatment of the AYA oncology population. Based in developmental theories and addressing identified population needs, these programs have the potential to greatly impact the AYA oncology population. In the future, more research is needed to hone in on specific needs not yet addressed for this population and research is needed to determine the impact of AYA specific programs. With increased focus on the unique needs of this population, AYA programs are likely to create impact that is essential to improving the AYA oncology population’s survival.

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