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## Caring for Young Adults with Cancer: A Systematic Review

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**Caring for Young Adults with Cancer: A Systematic Review**

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NURS 695: Alternate Plan Paper

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## Abstract

Young adulthood is unique period of life in which critical developmental milestones are achieved amid dynamic physical, emotional, and social changes. During this period of life, young adults are charged with establishing personal and social independence. When challenged with a cancer diagnosis, the already turbulent late teens, twenties, and thirties are dramatically and permanently altered. Hence, the needs of young adults vary from that of their pediatric and older adult counterparts. The aim of this systematic review of the literature was to identify what age-specific needs must be addressed by healthcare professionals to enhance quality of care and outcomes for this unique population of oncology patients. The following databases were searched from January 2010 to November 2019: Academic Search Premier, CINAHL, Medline, and Mav Scholar Advanced Search. Sixteen studies were identified and analyzed. Findings suggest that although various physical and psychosocial demands exist, needs related to fertility preservation, sexuality, peer relationships, education, employment, and financial support are foremost. As healthcare professionals who often partner with oncologists or oversee primary care for young adults, advanced practice registered nurses are in a unique and critical position to deliver these age-appropriate interventions. Information provided to this age-cohort must be individualized and include knowledge regarding adherence, long-term side effects, clinical trials, and complementary therapies. Utilization of technology and social media is vital throughout the continuum of care from diagnosis to survivorship or end of life. Healthcare professionals must recognize the vulnerability associated with young adulthood, know each patient's developmental and maturity level, and then appropriately implore educational and behavioral interventions.

*Keywords:* young adults, adolescents and young adults, AYA, cancer, oncology, needs, age-specific needs, quality of care, outcomes

## **Caring for Young Adults with Cancer: A Literature Review**

Young adult (YA) cancer patients and survivors have distinct physical, psychosocial, and informational needs that set them apart from pediatric and older adult patient populations (Zebrack et al., 2013). Though their younger and older counterparts have seen improvements in survival rates in recent decades, this population's mortality rates have remained relatively the same (Zebrack et al., 2010). In fact, cancer is the leading disease-related cause of death for this age cohort with approximately 70,000 patients aged 15-39 diagnosed with cancer each year (Nass et al., 2015). Multiple factors contribute to the poorer outcomes experienced by YAs, including diagnosis delays, lack of provider familiarity with YA cancer, low enrollment in clinical trials, inconsistent treatment approaches, and decreased adherence to treatment plans (Warner et al., 2016; Zebrack et al., 2010). Despite poorer prognosis rates, there are approximately a half a million survivors of either a childhood or adult-onset cancer living in the United States today (Hydeman et al., 2019). Accordingly, it is imperative for healthcare professionals (HCPs) to recognize their unique life circumstances. This review seeks to identify what age-specific needs must be addressed by HCPs to enhance quality of care and outcomes for this distinctive population of oncology patients.

### **Background**

For the purposes of this literature review, the population of interest was YAs with cancer aged 18 to 39 years. A challenge to studying this population is the inconsistency in which young adults are delineated from children, younger adolescents, and older adults (Hydeman, 2019; Zebrack et al., 2013). In the current litany of oncology research, the YA population can be defined as ages 18-39 as with this study, grouped with adolescents and defined as ages 15-39 as is done by several organizations such as the National Comprehensive Cancer Network (NCCN,

2019), or defined in some other manner. The lack of consistency exists for several reasons including personal variations among individual patient development and the chronicity of cancer as patients often deal with recurrent malignant disease across the various life stages.

Irregularities in delineating YAs from pediatric and older adult patients is partially due to the fact that no two YAs move through life transitions at the same pace. Though each person reaches developmental milestones at various times in life, there are noteworthy achievements YAs typically experience during this phase of life. These milestones often include formulation of personal identity and values, autonomy from parents and emphasis on peer, intimate, and sexual relationships, social and financial independence, educational attainment, and entrance and upward mobility in the workforce (D'Agostino et al., 2011; Galan et al, 2016). Stated more plainly, young adulthood is a period of life in which YAs “learn who they are, who they identify with, and what direction they want their lives to take” (Epelman, 2013, p. 325). It is well documented in the literature that YAs with cancer are a particularly vulnerable cohort of patients due to the disruption caused by a life-altering disease. Cancer and its related treatment frequently cause regression in physical, cognitive, and social development as YAs with oncologic disease lean on parents, loved ones, and caregivers for support (DeRouen et al., 2015; Zebrack et al., 2010). Understanding the vulnerabilities and needs of YAs with cancer is essential for HCPs in order to assess them in advancing quality of life and promoting survival outcomes.

### **Clinical Question**

Based on the above phenomena of interest, the following clinical question was developed to guide a systematic review of the literature: *Among young adults with cancer, what age-specific needs must be addressed by healthcare professionals to enhance quality of care and outcomes?* The purpose is to advance the understanding of the needs of YAs with cancer in order to further

guide evidenced-based interventions. Age-specific and needs-based interventions should aim to promote holistic care whether YAs are undergoing current cancer treatment, dealing with advanced disease, or navigating survivorship.

### **Clinical Significance for Advanced Practice**

Advanced practice registered nurses (APRNs) contribute significantly to the provision of healthcare overall. Though a vast majority of APRNs work as primary care providers (PCPs) for a wide array of patient populations, just over 1% of the approximately quarter of a million APRNs licensed in the U.S. practice specifically in the oncology specialty (Bishop, 2018). When a YA is faced with a cancer diagnosis, APRNs are in a unique and critical position to deliver age-appropriate interventions (Daniel et al., 2015). Considering many cancer centers have models of care that partner hematologist/oncologists with APRNs and since YA oncology care is frequently co-managed between oncology specialists and PCPs, it is imperative for APRNs to understand best practices when caring for YAs with cancer (Zebrack et al., 2010).

## **Methods**

### **Databases and Data Abstraction**

A comprehensive literature search was completed between the dates of 10/19/2019 and 11/16/2019. Databases searched included Academic Search Premier, CINAHL, Medline, and Mav Scholar Advanced Search. Specific databases, search restrictions, search date ranges, and general subjects covered by each database are included in Table 1 of the attached appendices. Search limits applied to all database searches included results from the years 2010-2019, full text availability, and articles published in the English language. An additional search limit that was applied if available via advanced search options included selecting scholarly or peer reviewed articles. Search terms used included “young adults,” “adolescents and young adults,” “AYA,”

“cancer,” “oncology,” “needs,” “age-specific needs,” “quality of care,” and “outcomes.” Key words were searched individually and in various combinations. Search dates, key words, and hits in respective databases are included in Table 2 of the attached appendices.

### **Search Strategies and Literature Review Process**

The number of article hits obtained for every keyword search in each of the databases was recorded, and searches with 25 or fewer hits were chosen for a brief review of titles and abstracts. Those articles whose title and/or abstract suggested its relevance to the phenomenon of interest and identified clinical question were marked for further review. To maximize the number of articles retrieved, reference lists of relevant articles were also reviewed for additional articles not found during the computerized data searches. After eliminating five duplicate articles, the review of article titles and abstracts as well as relevant articles from reference lists yielded 24 studies identified for further assessment for inclusion or exclusion in the literature review. Table 3 of the attached appendices lists the 24 studies as well as the rationale for inclusion or exclusion.

Beyond the search limitations previously listed, articles were eligible for inclusion in the literature review if study participants or the population of interest included young adults with a cancer diagnosis that were either undergoing current/active cancer treatment or that had completed cancer treatment. Articles were also included if the primary focus was on assessing one or more physical, psychosocial, informational, or other needs of the population of interest. For the purposes of this literature review, young adults were classified as persons aged 18 to 39. It was previously noted that significant inconsistencies exist across the oncology literature regarding how the young adult age group is defined. Frequently, adolescents and young adults with cancer are researched together and oncology literature frequently refers to this age cohort as

the 'AYA' population. Unfortunately, there is no clear consistency as to what age childhood ends and adolescence begins or as to when adolescence ends and young adulthood begins. Articles were excluded if the title and/or abstract indicated the article pertained predominantly to children or adolescents aged 0 to 17 or adults 40 and older. Articles were also excluded if oncology needs researched or discussed related to a specific cancer diagnosis (e.g., brain, breast, colon, etc.) as the literature review aim was to yield results that were generalizable to the entire YA cancer population. Of the 24 articles in Table 3 that were read in entirety, 16 articles met inclusion criteria. Table 4 lists each of the included articles and contains relevant study information including study purpose, sample characteristics and AYA age range, level of evidence, research methods and tools, study findings, and study implications. The Hierarchy of Evidence by Melnyk and Fineout-Overholt (2019) was used to evaluate the strength of the research evidence.

### **Summary of the Literature**

#### **Study Characteristics**

Despite the growing number of studies related to the clinical question, YAs with cancer continue to be an under-researched age cohort. In this systematic review, several studies gathered information from young adults with cancer as well as the HCPs who care for them. Others even included information gathered from family members, friends, and various caregivers of YAs with cancer. While quality publications by experts dedicated to caring for the YA population are numerous, high-level research including randomized controlled clinical trials (RCTs) as well as systematic reviews and meta-analysis of the RCTs are lacking. Areas for further research are addressed at the conclusion of this systematic review.

Design and quality of the included literature was varying. Due to the nature of subject being studied and the challenges of researching a highly mobile population, there was no



evidence obtained from RCTs. The highest level of evidence was from six well-designed cohort studies. Though three systematic reviews were included, none included evidence from RCTs. One qualitative study was included, and six articles relied on evidence from the opinion of authorities or reports from expert committees.

### **Synthesis of the Research**

After an in-depth review of the 16 articles that met inclusion criteria, the following summary of the literature was formulated. While the needs of YAs with cancer were classified in a variety of ways in each of the articles, all included scholarly publications specifically addressed the unique challenges of dealing with an oncology diagnosis in young adulthood. For the purposes of this review, age-specific needs of YAs with cancer were classified into three categories, including physical, psychosocial, and information needs.

### **Physical Needs**

Physical health is the condition of one's body and HCPs should consider the wide continuum of a YA's physical health determined by the presence or absence of disease and level of fitness. When challenged with a cancer diagnosis in young adulthood, patients experience devastating disruptions in typical physical growth and development (Zebrack et al., 2014). Moreover, young adulthood is often a time in which persons are creating lifelong habits as it relates to their physical activity and diet. Since cancer and the various treatments can have lasting impact on bodily functions, strength, and physical abilities, it is essential for HCPs to address the physical needs of YA cancer patients (Daniel et al., 2015). Physical needs that were noted routinely in the literature included needs related to physical activity, diet/nutrition, fertility preservation, and contraception.

### ***Physical Activity***

In July of 2010, the U.S. concluded its first longitudinal population-based study of the AYA population. The Adolescent and Young Adult Health Outcomes and Patient Experience Study (AYA HOPE) was conducted to better understand the unmet needs of AYAs with cancer as well as the sociodemographic and health-related factors linked to those unmet needs.

Between a quarter to a half of the 523 study respondents reported that being physically fit as an unmet need (Keegan et al., 2012). In a Canadian study, greater than 80% of the 243 survey respondents rated information related to exercise and physical fitness during cancer treatment at least an 8/10 in level of importance (Gupta et al., 2013). Research also suggests that YAs with cancer fail to meet Centers for Disease Control and Prevention (CDC) recommendations for physical activity, especially when compared to their healthy counterparts (Daniel et al., 2013).

Regardless of whether or not an individual has received a cancer diagnosis, the risks associated with a sedentary lifestyle are innumerable and include a higher susceptibility for metabolic, cardiovascular, and mental health diseases such as obesity, diabetes, hypertension, and depression. When the risks of a sedentary lifestyle are coupled with the profound impacts of a cancer diagnosis and its related treatment, the threat posed to the YA population is serious. For example, treatment protocols can have a detrimental impact on lean muscle development which in turn increases future propensity to injury and fatigue (Daniel et al., 2013). In collaboration with their oncology team and PCP, YAs should aim to meet CDC recommendations of 150 minutes of moderate-intensity or 75 minutes of vigorous-intensity aerobic physical activity per week. Muscle-strengthening activities involving all major muscle groups are advised at least twice weekly. YAs should modify physical activity as necessary based on their unique health and physical endurance status but recognize that it is generally accepted that with increased physical activity comes enhanced health benefit (U.S. Department of Health and Human Services, 2008).

Additionally, the NCCN recommends referral to a physical or other rehabilitation therapist as needed to address concerns related to physical health (2019).

### ***Diet / Nutrition***

American and Canadian YAs placed a similar emphasis on diet and nutrition as they did on physical activity. In the age-based studies just mentioned, up to a half of American respondents reported desiring more information related to diet and nutrition, and over three quarters of Canadian respondents rated information related to maintaining and health diet at least an 8/10 in level of importance (Gupta et al., 2013; Keegan et al., 2012). Adequate nutrition is essential to muscle and skeletal development, and a malignant disease and its related treatment can increase nutritional needs. However, researchers found that YA cancer survivors eat less than recommended amounts of fruits and vegetables and excessive amounts of fat. Consequently, YAs with cancer are often nutritionally deficient in essential vitamins and minerals including iron, folate, calcium, and vitamin D (Daniel et al., 2013). Though their nutritional intake is deficient, their caloric intake is frequently excessive which results in “more than one-third of AYA survivors who are a normal weight before diagnosis becoming overweight by the end of treatment” (Daniel et al., 2013, p. 676). NCCN guidelines recommend referral to a dietitian specifically trained in oncology to educate YAs on the diet and nutrition changes related to cancer and its treatment (2019).

### ***Fertility Preservation***

Though preservation of reproductive function is discussed in this section of physical needs, it should be recognized that fertility preservation is intricately intertwined with intimate relationships and sexuality. These subjects are appropriately discussed within the broader context of a psychosocial need. Understanding the potentially devastating repercussions of cancer and its

treatment on reproductive capability is of utmost importance for YAs with cancer. The potentially temporary or permanent damage to reproductive organs is most dependent upon factors including cancer type, treatment choice, and patient age (Fridgen et al., 2017). Fertility preservation for YAs with cancer is increasingly being referred to as the emerging field of *oncofertility*. For men, fertility preservation options include sperm or testicular tissue cryopreservation and/or gonadal shielding from radiation therapy. Similarly, for women, fertility preservation options include embryo, oocyte, or ovarian tissue cryopreservation and/or transposition and gonadal shielding from radiation therapy (Nass et al., 2016).

While HCPs may be unable to predict with absolute certainty if a patient's reproductive capabilities will return once treatment has commenced, they can counsel patients regarding the relative risks of certain surgical procedures, chemotherapy medications, and radiation treatments that are more likely to negatively impact one's future ability to reproduce. HCPs must also take into consideration the severity of malignant disease, approximate prognosis, and urgency at which treatment should be initiated (Zebrack et al., 2010). Subsequently, a patient-provider conversation would look significantly different in a patient with terminal disease than in one that has a more favorable prognosis. Especially for those patients in whom emergent treatment is necessary, it is likely that patients and loved ones will understandably shift their focus from reproductive function to survival. However, providers should anticipate that once the shock of a cancer diagnosis has had time to settle, the critical issue of reproductive capabilities will resurface (Gupta et al., 2013). Timing is important when considering reproductive potential and providing patients with individualized information as early on as possible is key. Many reputable organizations mirror recommendations published in the most recent NCCN Guidelines for AYA Oncology that suggest discussions regarding fertility preservation and the impact of the cancer

diagnosis and treatment on the patient's reproductive capacity to ideally occur at the time of diagnosis and certainly before initiation of treatment. Additionally, appropriate referral to reproductive medicine, gynecology, or endocrinology should be expedited (Nass et al., 2015; NCCN, 2019; Zebrack et al., 2015).

**Contraception.** Similar to conversations related to fertility preservation, discussion of contraception early on after a cancer diagnosis is vital. HCPs should be adept in discussing the serious physical, mental, and social consequences of an unplanned pregnancy for YA cancer patients. Particular attention should be paid to the teratogenic risks to the developing fetus, especially during active cancer treatment (ASCO, 2018). HCPs again must remember how this period of life is often one saturated with risk-taking behavior, including the increased likelihood of engaging in sexual risk-taking. Propensity to partake in risky sexual behavior combined with the mythical notion that they are unable to conceive or reproduce due to cancer or its related treatment, YAs often devalue the need for contraception. Moreover, even if HCPs are knowledgeable on contraception management techniques, misperceptions can lead to oversight. For example, HCPs may view YAs with cancer as too ill to engage in or have desire for sexual intercourse. Thus, not only must contraception be discussed with each and every YA patient, recommendations for appropriate contraception management must take into consideration developmental and social contexts (Fridgen et al., 2017; Gupta et al., 2016).

Reliable methods of contraception to discuss with patients include but are not limited to oral contraceptives, barrier contraceptives (condoms), long-acting reversible contraceptives (IUDs and subdermal implants), and emergency contraceptives (Plan-B) as well as permanent contraception (tubal ligation, vasectomy). Contraceptive counseling should include educating YAs on proper and consistent use as well as the risks and benefits associated with each method.

HCPs should also be knowledgeable regarding the risks associated with certain contraceptives (e.g., increased risk of venous thromboembolism with combined hormonal contraceptives) and contraindications of certain methods (e.g., avoiding hormonal contraceptives for patients with breast cancer). Personal preference, religious beliefs, and reproductive goals should be discussed with patients when mutually deciding upon the most appropriate contraceptive method.

Contraception needs to routinely be integrated into patient-provider conversations along the continuum of care, including at diagnosis, during treatment, and throughout survivorship (Fridgen et al., 2017).

### **Psychosocial Needs**

Psychosocial needs examined included those needs that relate to the cognitive, emotional, and social health and well-being of YA cancer patients. HCPs need to recognize each patient's cognitive and social development is unique and that emotional reasoning continues to develop well into a patient's mid-20s (Daniel et al., 2015). While certain studies separated psychological needs from social needs, the majority of publications, including a summary from the Institute of Medicine [IOM], blended mental and social health needs into the broader classification of psychosocial needs (Nass et al., 2015). Research highlighted evidence that considerable numbers of YAs have unmet psychosocial needs (Zebrack et al., 2013; Zebrack et al., 2014). Psychosocial aspects of care detailed below including needs related to mental health, substance abuse, relationships, sexuality, education, employment, and finances.

### ***Mental Health Support / Counseling***

For starters, HCPs should gather information related to each YA's pre-cancer mental health history as it may predict patterns of psychological distress and coping capabilities (Zebrack et al., 2014). Though the need for continual assessment of mental and emotional health

is important for patients of any age following a cancer diagnosis, it is imperative that YAs be connected to a mental health professional that is well versed in the unique challenges of dealing with a cancer diagnosis in young adulthood. In the AYA HOPE study, 56-75% of YAs with cancer reported they needed although did not receive mental health support from either a support group or a mental health worker (Keegan et al., 2012). In another 2013 study, researchers made the “observation that an unmet need for professional mental health services increases as AYAs reported more treatment-related symptoms” (Zebrack et al., p. 211). YAs may be increasingly prone to post-traumatic stress disorder (PTSD) and YA cancer survivors have higher rates of suicidality than their healthy, age-matched counterparts (Daniel et al., 2015).

A 2016 mixed methods systematic review identified various means of providing counseling or psychological support (Galan et al.) Firstly, there are a variety of mental health workers that can provide emotional support including psychiatrists, psychologists, social workers, counselors, and spiritual/religious counselors. Secondly, mental health topics that YAs with cancer more frequently needed assistance with was living with uncertainty and loneliness, dealing substance abuse, talking with overprotective parents, and expressing frustrations about how cancer has impacted their personal and sexual health. Not surprisingly, YAs often needed support in dealing with anxiety about cancer recurrence (Galan et al., 2016).

**Substance Abuse.** The concern of substance abuse in YA cancer patients is two-fold. Firstly, for the overall general U.S. population, alcohol, tobacco, and other drug use tends to peak during in the late teens and early twenties. In recent years, teen and young adult Americans have increased their use of marijuana and vaping (National Institute on Drug Abuse, 2015). Secondly, tobacco, alcohol, and other substances commonly interact with prescribed cancer treatment regimens and substance dependence can negatively impact organ health, especially

heart, liver, and bone health (Daniel et al., 2015). Since risky behaviors are more common in this age cohort, frequent assessment of substance abuse issues is a priority. For patients with a history of substance abuse or for those showing signs or symptoms of abuse, HCPs should make referrals to appropriate substance abuse management programs, including tobacco cessation (NCCN, 2019). Highly stressful times (e.g., diagnosis or recurrence) can trigger substance abuse, and without access to higher order cognitive functioning, YAs may be less able to control impulses. Although HCPs should be forthright and open regarding substance abuse, they must remember to approach the topic with sensitivity and confidentiality in mind in order to establish rapport with the YA patient (Daniel et al., 2015).

### ***Peer Relationships***

As persons transition from childhood and adolescence into young adulthood, their peer relationships become increasingly central in their lives. Any cancer diagnosis, regardless of its required treatment regimen, is going to set a YA apart from their healthy peers (Warner et al., 2015). While many of their age-matched counterparts appear to be basking in the carefree world of a college education, getting married or starting their families, and/or gaining upward mobility in the workforce, YAs with cancer often remain stagnant or regress in their education, vocational, or familial aspirations. As a cancer diagnosis flips their worldview on its axis, their peers continue on in the fast-paced American lifestyle. Therefore, HCPs should acknowledge the reality of strained peer relationships and validate the YA's feelings of frustration, envy, and/or ostracization (Epelman, 2013). YAs must be allowed the opportunity to engage in typical peer relationships as much as possible. Often, when young adults with cancer are able to attend classes or continue to work, their peer relationships are less disturbed (D'Agostino et al., 2011).



**YA Connection.** While many YAs report a desire to meet and socialize with others in their age group who have also dealt with the complexities of a cancer diagnosis, the literature on this topic is mixed. Some studies have revealed that YAs with cancer perceive their ability to interact with other YAs with cancer as more important than even some relationships with close family and friends (D'Agostino et al., 2011; Warner et al., 2015). Although other literature acknowledged that isolation from peers with cancer was a feature of the YA experience, not all deemed meeting an ill peer relationship necessary since they placed greater emphasis on re-assimilating into their previous network of peers (Gupta et al., 2013). Support groups specifically designed for YAs are one of the most prominent ways that healthcare organizations and cancer centers can connect YAs to their peers that are also dealing with a cancer diagnosis. HCPs should offer a variety of platforms, including one-on-one meetings, in-person support groups, and online social media chatrooms, since all are essential to meeting the unique psychosocial needs of YAs (Gupta et al., 2013; Warner et al., 2015). YA support groups provide a unique opportunity to discuss the age-specific needs outlined throughout this literature review. Case reports of innovative ways to connect YAs show promise for improving YA psychosocial health. For instance, YAs may benefit from expressive art therapy or camps/retreats that are specifically dedicated to this underserved populations (Warner et al., 2015; Zebrack et al., 2013).

### ***Family Relationships***

Relationships with family members can remain stable following a cancer diagnosis; however, often familial relationships experience certain levels of strain. As persons emerge into young adulthood, they naturally desire to be treated as adults. Though young adulthood is typically a time of gaining independence from parents, the devastating effects and continual demands of an oncologic disease frequently cause YAs to regress and once again become

dependent on their parents for financial and other practical supports. Alarmed by their child's life-altering and potentially life-threatening disease, parents of YAs in the late teens and early 20s instinctively become protective of their children (Epelman, 2013). However, when parents or authority figures become overbearing, YAs may feel their loved ones' longing for control undermines their independence. Conflict and resentment may ensue and impact the YA's choice of treatment or hinder adherence to the recommended treatment regimen. Some YAs, usually those in their 30s, may be trying to juggle the demand of caring for an aging parent (Zebrack et al., 2010). Also, siblings of YAs with cancer have been found grapple with resentment as it is commonplace to experience loneliness, anger, and vulnerability when so much attention is being paid to their ailing sibling (Epelman, 2013).

**Parenting and Pregnancy.** For some YAs, a cancer diagnosis may come after they have had children or even amid a current pregnancy. Though it is rare to have cancer in pregnancy, when it happens, many practical and ethical challenges ensue for patients and providers. Coordinated, multidisciplinary care between oncology and maternal fetal medicine specialists is critical to the health outcomes of mother and child (ASCO, 2018). For YA patients with infants, toddlers, and school-age children who need supervision, many report childcare as an unmet practical support need (Nass et al., 2015). By providing assistance with practical support needs, HCPs have the opportunity to enhance adherence to the recommended treatment protocol (Zebrack et al., 2010). Referral to a counselor, psychologist, or other mental health professional may be beneficial for older children who are attempting to cope with a serious or terminal illness of a parent (Nass et al., 2015). HCPs should be aware that YAs aged 30-39 were more likely than YAs in the late teens and 20s to report an unmet need for family counseling (Zebrack et al., 2013).

### ***Intimate Relationships and Sexuality***

Finding a romantic companion or life partner is a significant landmark for many YAs (Nass et al., 2015). For some, uniting in marriage to their loved one is a major social milestone. However, just as a cancer diagnosis places burdens on peer and familial relationships, so too does it impact romantic and spousal relationships. While nominal research is available on the topic, one systematic review cited that “25% of AYA HOPE respondents reported that cancer negatively impacted their relationship with their spouse/significant other” (Warner et al., 2015, p. 1034). Additionally, “AYAs with cancer were more likely to have divorced or separated than the controls” (Warner et al., 2015, p. 1033).

For YAs, sexuality is a complex construct impacted by several factors such as body image, gender identity, sexual orientation, sexual desire, and sexual function. Also, young adulthood is often a period sexual exploration and formulation of intimate relationships. Alterations in sexuality and intimacy occur more often in YAs with cancer because of the disease, its related treatments, and its associated psychological distress. Body image concerns can be related to weight gain or loss, hair loss, and/or body disfigurement from surgery or other treatments (Zebrack et al., 2010). However, the topics of sexuality and intimacy are regularly neglected by HCPs due to time constraints and comfortability in addressing a sensitive topic (Epelman, 2013; Gupta et al., 2016). Per recommendations from NCCN (2019) guidelines, HCPs must assess YAs for gender expression and sexual preferences as well as educate them regarding safe sex practices. YA cancer patients, especially those on an active treatment regimen, have an increased likelihood of contracting sexually transmitted infections (STIs) because of their weakened immune systems (Fridgen et al., 2017). One comprehensive Canadian cancer center who care for approximately 1300 newly diagnosed AYAs each year outlined strategic methods

for addressing sexual health. Not only does their strategy include normalizing discussions of sexuality, they partner with sexual medicine specialists. For instance, research supports the use to pelvic floor physiotherapy for women to decrease symptoms such as vaginal dryness and stenosis (Gupta et al., 2016).

### ***Education***

For many teens and YAs, a college education opens doors to career opportunities and future financial stability. If YAs are challenged with a cancer diagnosis before entering or completing an advanced education, the repercussions can be innumerable. Often times, YAs must place their educational aspirations on hold because of the demands of their cancer treatment regimen. Being absent from educational institutions denies YAs the opportunity for progression toward a degree and availability of an important social network (Warner et al., 2015). Not only can it be psychologically straining to watch their peers graduate, YAs are still straddled with student debt and the threat of being unable to return to their studies. Generally, most YAs with cancer reported cancer as having an adverse impact on their educational and employment aspirations (Nass et al., 2015). HCPs should recognize that formal neuropsychological evaluation is recommended for patients who show evidence of impaired educational progress (NCCN, 2019).

### ***Employment***

Just as YAs face challenges in their educational goals, they similarly encounter interruptions and setbacks in their careers. Unfortunately, researchers show that among YA cancer survivors who were 35 or younger at time of diagnosis, up to a quarter of survivors experience employment struggles such as discrimination or bias in the workplace (D'Agostino et al., 2011). The age at which a YA is diagnosed is likely to be correlated with the career obstacle that

needs to be overcome. Some YAs may still be finishing their education, searching for their first job, or in a short-term position with suboptimal benefits while others are more commonly attempting to build a respectable reputation and striving for promotion. Without work, the resultant financial losses pose a significant threat to personal and familial economic status. YAs have also been found to experience the phenomenon of “job lock” due to their inability to pursue a career of choice if they have to stay in a current role due to scheduling issues or benefits (Nass et al., 2015). Thus, HCPs play an instrumental role in helping YAs refine their employment goals, making sure they are appropriate and attainable. Since failure to return to work is a significant marker of long-term quality of life, the benefits of employment should be underscored. Not only can employment help patients economically, returning to work can be seen as a step in the right direction on one’s journey into survivorship (Gupta et al., 2106). Though YA patients with a favorable diagnosis may voice their opinion to only return to work at full capacity upon treatment completion, HCPs should discuss the benefits of part-time employment as allowable to ease the eventual transition back into full-time work (Cancer and Careers, n.d.). For those YAs with less favorable prognoses, appropriate referral to mental health professionals to lessen the psychological impact of their inability to attain career aspirations may be warranted (Warner et al., 2015).

### ***Finances***

Financial support is understandably dependent upon the YA’s financial status and situation at time of diagnosis. While some YAs may still be financially dependent upon their parents, others may have already been financially independent for years with dependents, mortgages, or other debts. The financial burden of a cancer diagnosis cannot be understated. Beyond medical expenses (medical insurance, out-of-pocket costs, co-pays, deductibles,

prescriptions, travel to appointments), many YAs need assistance in affording transportation, parking, prostheses, wigs, and childcare. During treatment and throughout survivorship, YAs have recognized the impact of loss of wages due to missed work and the increased costs of adhering to a healthy lifestyle such as financial expenses related to gym memberships and healthy foods, vitamins, and supplements (D'Agostino et al., 2011; Landwehr et al., 2016; Nass et al., 2015).

One 2016 study attempted to quantify the financial toxicity YAs experience by retrospectively analyzing grant applications of 334 cancer survivors aged 19-39. When compared to healthy, age-matched peers, “financial indicators of YA cancer survivors are worse in many domains [... as] cancer has a devastating and age-specific impact on the finances of YAs” (Landwehr et al., p. 863). That same study highlighted YAs as the most likely of any age cohort to be uninsured which has serious implications since poorer health outcomes are often experienced by the economically disadvantaged. Moreover, even though preservation of reproductive capacity is repeatedly ranked high in importance to YAs, fertility preservation expenses are rarely covered even when YAs have insurance coverage. Since YAs with cancer have lower incomes and net worth yet higher medical debt, the psychosocial implications of increased anxiety related to financial status is critical (Landwehr et al., 2016; Warner et al., 2015). Financial burden can continue on for years following completion of cancer treatment since a pre-existing oncologic condition may infringe upon one's ability to attain medical, life or other forms of insurance as well as other various healthcare benefits (D'Agostino et al., 2011). With assistance from team members such as social workers who are well versed in financial resources, HCPs should connect YAs with the numerous governmental or non-for-profit agencies who can provide grants and/or financial relief (Landwehr et al., 2016).

## **Informational Needs**

Plainly stated, informational needs are the facts or materials YAs desire and expect to be provided following a cancer diagnosis. Informational needs are dynamic and ever-changing throughout the continuum of care. The literature consistently exposed unmet information needs of YAs with cancer (Keegen et al, 2012). Central to the notion of informational needs is the concept of health literacy. Knowing that lower levels of health literacy are correlated with decreased patient understanding, scholars have suggested adopting a separate definition of cancer health literacy considering the complexities that underly oncologic illness (Gupta et al., 2016). Though specific YA informational needs are detailed below, healthcare organizations can improve their overall ability to meet YA informational needs by creating online patient education resources tailored specifically for the YA patient population (Gupta et al., 2016).

### ***Individualized Cancer Information***

While HCPs in the oncology specialty may encounter patients with serious malignant disease on a routine basis, it is obligatory to provide every YA information about their specific cancer, treatment recommendations, and future impact of the disease and treatment on their physical, reproductive, and mental health. Of the 16 included publications, a majority included individualized cancer information as a main topic of discussion (see Table 5 in the attached appendices). A thorough family history should be gathered with referral to a genetic counselor when appropriate so that each YA's unique genetic profile is understood (NCCN, 2019). Moreover, YAs desire the chance to talk about feelings related to their cancer and guidance on how to relay individualized cancer information to their close family members, friends, and colleagues (Zebrack et al., 2010). There is a need for information to be divulged in an age- and

developmentally-appropriate manner, taking into consideration the patient's literacy and maturity level (Warner et al., 2015).

**Side Effect Management.** While there are a host of physical and psychosocial side effects that result following cancer diagnosis and its treatment, it is imperative that YAs be informed of the short- and long-term side effects that are most likely to impact them individually. As compared to YAs who only completed surgery to treat their oncologic disease, YAs who were treated with chemotherapy had greater unmet needs in regard to understanding the long-term side effects of treatment. Additionally, YAs should understand that as their treatment intensifies so too does their likelihood for increased side effects (Galan et al., 2016). Mortality indices are less favorable for cancer survivors largely because cancer treatments increase susceptibility to second primary cancers, cardiovascular disease, and other chronic health problems in the future (Nass et al., 2015).

**Adherence.** Since adherence is central to enhanced patient outcomes and favorable prognoses, its significance should be emphasized early and often (Galan et al., 2016). "It is known that YA rates of treatment non-adherence are high, ranging from 27-60%, and are likely higher than any other cancer population" (Hydeman et al., 2019, p. 35). HCPs should individually identify barriers that could interrupt appropriate follow-up care. In particular, YAs financial status should be reviewed since medical nonadherence has been correlated with financial hardship (Landwehr et al., 2016). Especially for YAs with a greater disease burden, facilitating transportation services can help satisfy unmet needs and improve adherence (Zebrack et al., 2013). HCPs should recognize that emotionally distressed YAs are at risk for poor adherence (Zebrack et al., 2014). YA program models should include interventions that



encourage adherence to recommended evidenced-based treatment protocols (Nass et al., 2015; Zebrack et al., 2010).

### ***Utilizing Technology and Social Media***

Though HCPs cannot assume that every YA is technologically savvy, in general, HCPs should understand that YAs are often familiar with digital technology and social media. Online data is an informational need of YAs, and in comparison to YAs in the late teens treated in pediatric settings, YAs treated in adult settings reported access to age-appropriate internet sites as an unmet need (Zebrack et al., 2013). Consequently, age-specific interventions should employ technology as a way to meaningfully engage the YA as a partner in their care (Daniel et al., 2015; Warner et al., 2015). For instance, researchers show that patients and HCPs alike focus heavily on diet and exercise throughout survivorship (Galan et al., 2016). One way for HCPs to increase the numbers of YAs they reach is to provide “distance-based delivery methods that use the internet and smart phone apps that are designed to match the developmental stage and interests of the participants” (Nass et al., 2015, p. 191). With the overabundance of information available online, including untrustworthy sources, HCPs should create a repository of reputable online resources for YAs (Gupta et al., 2016; Warner et al., 2015). Leveraging online resources can improve patient education, communication with HCPs, and enrollment in clinical trials (Nass et al., 2015; Zebrack et al., 2013).

### ***Complementary and Alternative Therapy***

Integrative medicine approaches utilizing complementary or alternative medicine, often referred to as CAM, is an adjunctive form of treatment that interests many YAs with cancer. While complementary treatments are used in combination with standard medical care, alternative treatments are used instead of mainstream or Western medicine (National Cancer Institute [NCI],

2019). Examples of CAM include nutritional supplementation, acupuncture, massage, and tai chi just to name a few (NCI, 2019). Well many studies in this literature review referenced YA interest in CAM, rigorous research regarding integrative therapies are lacking. In one 2013 American study, researchers found YAs aged 20-29 to be the largest proportion of survey respondents reporting an unmet need for CAM services (Zebrack et al.). For YA patients interested in or currently using CAM therapies, honest communication with HCPs is critical to patient safety and experience. Although many forms of CAM have been deemed safe and effective, others can pose serious health risks (NCI, 2019). HCPs should assist patients in realizing that labeling a product as natural does not necessarily suggest it is safe. Moreover, some forms of CAM can interact adversely with traditional cancer treatment protocols (NCI, 2019).

### ***Clinical Trial Enrollment***

Several of the articles included in this systematic review mentioned low clinical trial enrollment as a barrier to improved outcomes for YAs (Zebrack et al., 2010). Statistics related to clinical trials are staggering with only 14% of cancer patients aged 15-39 enrolled compared to 60% for their pediatric counterparts. Additionally, while 34% of YAs in their late teens aged 15-19 were enrolled, only 3% of YAs aged 35-39 participated in clinical trials (Nass et al., 2015). Several factors are cited for prohibiting progress in access to and enrollment in clinical trials for YAs. For one, the inconsistencies in age categorization of YAs make it challenging to divide patients into subsections for research. Additionally, as YAs are a highly mobile and geographically disperse population, recruiting and retaining them for research is difficult (Nass et al., 2015). The NCCN recommends offering enrollment into any open clinical trials while continuing to provide best practices as it relates to supportive care measures (2019).

### *Survivorship / Follow-Up Care*

In the U.S. adult population, there are approximately a half a million AYAs aged 15-39 who are survivors of a previous child- or adult-onset cancer (Hydeman et al., 2019). Increasingly, patients are being educated on how to manage cancer as a chronic or ongoing illness such as heart disease or diabetes. HCPs should recognize the contrast of living after cancer as compared to living with cancer. For a substantial portion of YAs, in the months and years following their original cancer diagnosis, they experience cycles of disease remission, with full or partial response to treatment, and disease recurrence when their cancer grows or spreads (American Cancer Society, 2019).

In young adulthood, survivorship is a period of mixed emotions. Though many YAs experience significant relief following the completion of active treatment with surgery, radiation, and/or chemotherapy, others fear being disconnected from their team of HCPs (Epelman, 2013). In a recently published 2019 study, researchers innovatively utilized a concept mapping design to explore salient concerns of AYAs transitioning into survivorship care (Hydeman et al.). Beyond coping with physical and cognitive treatment effects as well as psychosocial concerns, a major emerging theme was adjusting to a new normal. This theme of a changed perspective recurred often throughout the literature, though evidence is inconclusive if the challenges of a cancer diagnosis inhibit a positive outlook or allows YAs to grow stronger as they discover meaning and their life's purpose (Epelman, 2013). As YAs transition into survivorship, the IOM strongly suggests creation of customized survivorship care plans (SCPs) that incorporate evidenced-based surveillance guidelines (Nass et al., 2015). Each patient's SCP should provide detailed information regarding intervals for follow-up visits and testing, recommendations for managing

long-term side effects, and education about concerning signs of disease recurrence (Hydeman et al., 2019; Zebrack et al., 2010).

Regardless of YA program design, it is always imperative for oncology providers to partner with PCPs when providing ongoing provision of care following a cancer diagnosis (Nass et al., 2015). In a 2013 single quantitative study of 243 Canadian YAs with a median age of 28, 92% of survey respondents had a PCP and 87% continued to see their PCP for general health issues. However, fewer than 20% felt comfortable seeing their PCP for their oncology follow-up care (Gupta et al.). Hence, the triad of collaboration between the oncology team, the PCP, and the YA is important.

### ***Palliative Care and End of Life Support***

A grave reality faced by many YAs with cancer is confronting their own mortality. For many in the general population, one's 20s and 30s is a period in life in which people feel they are invincible and have consequently never had serious conversations about end of life. Since many HCPs also see this age group as relatively healthy, they often fail to consider a malignant disease when patients present with common complaints such as abdominal pain or headache. As a result, it is commonplace for YAs to receive a cancer diagnosis when the malignant disease is in advanced stages. As cancers are more difficult to treat once they have metastasized to distant organs, there is a less favorable prognosis for this subset of patients. Greater burden of disease is not surprisingly correlated with increased dependence on HCPs, family, and friends for physical, emotional, and financial needs (Nass et al., 2015). HCPs should anticipate that unlike older adults with advanced cancer who cope by reflecting back on their life's achievements, YAs experience anticipatory grief over life accomplishments and milestones that are unattainable

(Gupta et al., 2016). For YAs who are parents, preparing their children for the loss of a parental figure is understandably distressing and challenging (Nass et al., 2015).

While benefits exist in referring patients to palliative and end of life/hospice services, a staple of care is helping YAs with advanced cancer understand the distinction between the two. YAs might refuse palliative care thinking it is a sign of impending decline. On the contrary, palliative care providers are instrumental in their expert provision of symptom management, especially amid high levels of disease burden. A competent palliative care team can assist YAs with issues such as pain management, emotional coping skills, and optimal rehabilitation (Nass et al., 2015). When a YA's prognosis becomes less favorable, HCPs should adopt honest and compassionate communication styles encouraging discussions regarding end of life planning at an appropriate time. Discussions should include information about advanced directives and assistance with completing paperwork such as a living will or medical power of attorney (NCCN, 2019).

### **Discussion**

A summary of the physical, psychosocial, and information needs of YA cancer patients analyzed in this systematic review is compiled in Table 5 of the attached appendices. Of the three needs categories, the literature consistently cited psychosocial needs as the most salient to be addressed throughout young adulthood. Within the broader psychosocial needs' category, the subcategories of peer relationships, education, employment, and finances were most frequently mentioned (D'Agostino et al., 2011; DeRouen et al., 2015; Epelman, 2013; Galan et al., 2016; Keegan et al., 2012; Nass et al., 2015; Warner et al., 2015; Zebrack et al., 2010). The interconnectedness of psychosocial needs is prominent as literature underscores the impact of education on employment as well as the influence of employment on financial status. In regard to

needs associated with relationships, the maturity level of and social milestones reached prior to one's original cancer diagnosis considerably influences what type of relational support each YA will need (Epleman, 2013; Galan et al., 2016; Nass et al., 2015). Confrontation with a life-altering and sometimes life-limiting oncology diagnosis causes profound emotional stress. Research highlighted how the YA population specifically reports unmet needs for referral to professional mental health services (Zebrack et al., 2013). Mental health professionals with specialized training are vital in helping YAs traverse through a life period stressed by risk-taking behaviors. By mitigating or minimizing risks associated with intimate relationships and substance abuse, YAs can experience improved psychosocial health (Daniel et al., 2015; Gupta et al., 2016).

Despite the broad category of psychosocial needs dominating in the YA literature, of the 17 specific subcategories of needs identified (physical activity, diet/nutrition, fertility preservation, contraception, mental health, peer relationships, family relationships, intimate relationships, education, employment, financial support, individualized cancer information, technology, CAM, clinical trial enrollment, survivorship, and palliative and end of life care), the desire for YAs to receive individualized information related to their specific cancer diagnosis was the most frequently cited main topic of discussion (D'Agostino et al., 2011; DeRouen et al., 2015; Galan et al., 2016; Gupta et al., 2013; Gupta et al., 2016; Keegan et al., 2012; Warner et al., 2015; Zebrack et al., 2013; Zebrack et al., 2014). Since diagnosis with a malignant disease is often a YAs first serious encounter with the healthcare community, studies recognize how essential it is for HCPs to have comprehensive discussions about the impact cancer and its related treatment at the time of diagnosis. YAs informed about their personal risks and benefits

of treatment options felt better prepared to make treatment-related decisions and to discuss personalized information with their loved ones (D'Agostino et al., 2011; Galan et al., 2016).

Since the ultimate goal of this systematic review was identifying age-specific needs in order to enhance quality of care and outcomes, HCPs should recognize what needs are most closely linked to experience and outcomes. Overall, the literature reported how YAs sought to be treated as adults and as partners in their own care (Hydeman et al., 2019). Though YAs desired for HCPs to treat them with compassion, they loathed parents and providers that were overbearing or patronizing (Epelman, 2013; Warner et al., 2016). Key elements of improving YA outcomes include early diagnosis, timely referral, care provision by HCPs knowledgeable about age-specific needs, and increased enrollment in clinical trials (Nass et al., 2015; Zebrack et al., 2010). HCPs should recognize that YAs who reported more unmet needs were also those found to have decreased quality of life (DeRouen et al., 2015), though these needs change across the continuum of care (Galan et al., 2016).

### **Limitations**

Overall, while numerous rigorous studies have been completed in recent years to address the unique needs of the YA oncology population, there are limited high level studies published that address YA needs and YA models of care. Many included studies utilized convenience sampling or expert opinion, which provides less generalizability of results. Well-designed RCTs as well as systematic reviews and meta-analyses of RCTs would certainly enhance the strength of the research. Some aspects of this patient population that make it difficult to study are the poorly defined age limitations of what constitutes a YA and the fact that YAs are a highly mobile and geographically dispersed age cohort (Daniel et al., 2015).

For the purposes of this systematic review, articles were not excluded if the study was conducted in another country besides the United States. It should be noted that healthcare intuitions in different nations may vary in their age categorization of AYAs/YAs as well as their terminology used to discuss this population (Zebrack et al., 2010). However, by including these articles, quality data was integrated to generate ideas about how YA programs in the U.S. can incorporate various program strengths with the ultimate goal of improved quality of care and patient outcomes. It should be noted that the variability of healthcare system design, regardless of its location of origin, has the capability to impact data, particularly when much of the data gathered was from surveys completed by YAs. For example, YAs in Canada have universal health care (Gupta et al., 2013) may have cited less need for financial support than their American counterparts.

### **Implications for Future Practice**

Clinical practice and educational recommendations are vital to addressing the original clinical question posed in this systematic review of the literature. Additionally, the health policy implications as well as areas for further research were identified for the underserved, vulnerable population of YAs with cancer.

### **Recommendations for Enhancing Quality of Care for Young Adult Cancer Patients**

When HCPs promote a sense of normality for YA cancer patients, they minimize the disruption that a cancer diagnosis causes which allows for this patient population to develop through young adulthood in an ordinary fashion. To do this, oncology HCPs should strive to adapt flexible healthcare delivery approaches such as telehealth visits or online communication via patient portals. HCPs should also modify their patient care approach to the maturity and independence level of each unique young adult patient. However, when the severity of disease



or rigor of treatment substantially impedes on day to day living, HCPs should put in place practical and informational supports that allow cancer patients to keep up socially and developmentally as much as possible with their peers (D'Agostino et al., 2011). Methods of referral to specialty care or resources in the community should be established in order to grant timely access to various HCPs (Zebrack et al., 2010).

Quality of care is enhanced when HCPs recognize how age-specific needs and priorities shift based on timing from diagnosis and patient status. In the period of time immediately following a cancer diagnosis, YAs are more focused on the complexities of treatment and provision of their care. As time passes, YAs tend to focus on psychosocial issues including what survivorship looks like and what direction they want to go in life (Galan et al., 2016). When HCPs identify individual needs and provide needs-based tailored care, YAs can enjoy an enhanced cancer care experience (Gupta et al., 2013). One recommendation for enhancing quality of care issued via a consensus-based position statement was appointment of an AYA champion. Champions can provide education to fellow HCPs as well as be a resource to other institutions throughout the community to coordinate care among a variety of healthcare services (Zebrack et al., 2010).

### **Recommendations for Improving Patient Outcomes for Young Adult Cancer Patients**

The most obvious opportunity for improving outcomes for YAs with cancer is to diagnose malignant disease in its initial stages. Especially in the primary care setting, healthcare providers need to routinely include cancer as a differential diagnosis when addressing patient complaints during acute visits and annual health maintenance exams (Zebrack et al., 2010). HCPs must remember that malignant neoplasms are the fourth leading cause of death for ages 15-24, fifth leading cause of death for ages 25-34, and the second leading cause of death for

those aged 35-44 (CDC, 2017). Ensuring YAs have a system in place for coordinating specialty and primary care with their oncology team and PCP is essential. Not only does this collaboration provide improved provision of the patient's overall health status, YAs have lower levels of distress when needs are collectively addressed (Gupta et al., 2013). Beyond collaboration with the YA's PCP, fostering collaborative partnerships with other healthcare specialists and systems can provide comprehensive care and additional resources for patients (Nass et al., 2015). Since YAs encounter issues with bias or discrimination, appropriate referral to legal services can improve patient status (Zebrack et al., 2010).

After a cancer diagnosis, open communication also provides opportunity of improved patients outcomes. During active treatment with surgery, chemotherapy, and/or radiation, the success of treating a malignant disease is profoundly impacted by a patient's adherence to the chosen treatment regimen. Hence, it is recommended that providers emphasize the significance of adherence in a nonpunitive manner (D'Agostino et al., 2011). As for the recommended structure to utilize when creating or enhancing a young adult oncology program, both age-specific YA needs and organizational capacity should be taken into consideration. Large, comprehensive cancer centers may have the ability to create independent programs specifically for the AYA/YA population or house their program within a pediatric and/or adult oncology outpatient center or hospital. Organizations with fewer resources who care for smaller volumes of YA oncology patients may adapt models where patients receive medical care from either an adult or pediatric oncologist yet have support programs specifically designed to address YA needs (D'Agostino et al., 2011; Zebrack et al., 2010). Regardless of program design, healthcare organizations should have a system in place to monitor and measure patient outcomes, ensuring they are informed by best practices (Nass et al., 2015).

## **Education Recommendations for HCPs**

YA programs need to highlight the importance of HCPs being educated on information specific to the YA population. Especially at the time of diagnosis and during the initial patient encounters, HCPs should recognize that cancer is likely to be the first serious illness YAs have dealt with. Additionally, where a patient lies on the ill-defined YA age spectrum is correlated with their individual needs. Clearly, the needs of an 18-year-old freshman in college will be in stark contrast to a 39-year-old who is married with children and is nearly two decades into their career (Zebrack et al., 2013). A 2016 systematic review of AYA cancer survivor needs reported that YAs in their late teens and early 20s emphasized the need for support from family and friends, flexibility in scheduling treatments to fit their lifestyle, and information regarding fertility preservation. Conversely, YAs in their 30s more frequently cited the need for financial support and information related to long-term side effects as well as the possibility of getting another cancer (Galan et al., 2016; Zebrack et al., 2013).

HCPs should be educated on proper patient counseling techniques. Since it is common to question figures of authority when entering into adulthood, HCPs should avoid communication that is perceived as patronizing to the YA with cancer (D'Agostino et al., 2011). For example, rather than emphasizing what a patient cannot do (e.g., cannot attend a concert during peak flu season due to immunosuppression), highlight what they can do (e.g., adhere to proper hand hygiene when in the presence of family and friends). Finally, HCPs must recognize their contribution to the provision of care for YAs with cancer. It is unreasonable to posit that any one HCP could expertly speak to all of the above discussed YA needs. Understanding one's own strengths and weaknesses and leveraging other members of the multidisciplinary care team is essential to comprehensive YA cancer care (Gupta et al., 2016).

## **Health Policy Recommendations**

Advocating for the age-specific needs of YAs with cancer is an instrumental way to enhance quality of care and outcomes for this vulnerable patient population. Perhaps the greatest stride in healthcare policy for YAs with cancer occurred approximately a decade ago with the passing of the 2010 Affordable Care Act (ACA). The most notable portion of ACA legislation was the provision allowing YAs to remain on their parents' insurance until the age of 26 years. Additional stipulations of the ACA that continue to improve access and affordability to healthcare include those that "require many health insurance plans to cover the costs of routine medical care provided within clinical trials, prohibit cost sharing for certain preventative services, prohibit annual or lifetime limits on essential health benefits, and ban exclusions on pre-existing conditions" (Nass et al., 2015, p. 192). HCPs would serve patients well to continue to support state and federal legislation that offer protection and benefits for YAs with cancer.

## **Areas for Further Research**

Whether the research is aimed at further identification of YA needs or on how to best implement age-specific YA interventions, research needs to take into consideration contextual factors such as developmental, educational, behavioral, social, and environmental contexts (Daniel et al., 2015). Considering the variabilities that exist among age subcategories within the broader AYA/YA population, it is recommended that research be conducted on subgroups to better understand how age-specific needs change with time (Warner et al., 2015). While this systematic review did not focus on the impact of primary cancer source on age-specific needs, generating research on the extent to which cancer type influences YA well-being would be of benefit (Warner et al., 2015). Another area for further research is identifying subgroups of the YA population that have greater needs. Few researchers studied sociodemographic variables

such as race/ethnicity, language preference, education level, sexual orientation/gender identity, or marital status. Collecting such sociodemographic data could further assist with appropriate resource allocation (DeRouen et al., 2015). In regard to improving patient outcomes, several publications cited the need for research in the creation and dissemination of evidenced-based guidelines and standards of care for the YA population (Nass et al., 2015; Zebrack et al., 2010).

### **Conclusions**

In conclusion, HCPs should strive to develop a model of care that allows for YAs with cancer to be independent partners of care, motivated to enhance their physical and psychosocial well-being. In this systematic review of the literature, evidence overwhelming supported the need for individualized provision of care by considering the developmental and social maturity of every YA patient with cancer. HCPs should be cognizant of age-specific needs of this underserved population including information regarding fertility preservation, peer familial relationships, education, employment, technology utilization, and enrollment in clinical trials. Ultimately, adapting practices that emphasize needs-based interventions is key to successfully addressing issues and concerns that emerge in young adulthood.

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- Zebrack, B., Block, R., Hayes-Lattin, B., Embry, L., Aguilar, C., Meeske, K., Li, Y., Butler, M., & Cole, S. (2013). Psychosocial service use and unmet need among recently diagnosed adolescent and young adult cancer patients. *Cancer*, *119*(1), 201–214.  
<https://doi.org/10.1002/cncr.27713>
- Zebrack, B., Corbett, V., Embry, L., Aguilar, C., Meeske, K., Hayes-Lattin, B., Block, R., Zeman, D. T., & Cole, S. (2014). Psychological distress and unsatisfied need for psychosocial support in adolescent and young adult cancer patients during the first year following diagnosis. *Psycho-Oncology*, *23*(11), 1267-1275.  
<https://doi.org/10.1002/pon.3533>

## Appendix

**Table 1***Database Search Description*

<b>Database (or Search Engine)</b>	<b>Restrictions Added to Search</b>	<b>Dates Included in Database</b>	<b>General Subjects Covered by Database</b>
1. Academic Search Premier (ASP)	Full text; Scholarly (Peer reviewed) journals; English language; Document type - Articles	Previous 10 years: 2010-2019	The Electronic Library of Minnesota provides free access to ASP to anyone in Minnesota. The database provides citations, abstracts to articles, and full text articles from over 4,600 publications covering almost every academic subject.
2. CINAHL Plus with Full Text (CINAHL)	Full text; English language; Research article; Peer Reviewed	Previous 10 years: 2010-2019	CINAHL Plus with Full Text provides full text access to nursing e-books and journals as well as citations and abstracts to articles, books, dissertations, proceedings, and other materials about all aspects of nursing and allied health. Aspects covered include cardiopulmonary technology, emergency service, health education, medical/laboratory, medical assistant, medical records, occupational therapy, physical therapy, physician assistant, radiologic technology, social service/health care, and more.
3. Medline	Full Text; English Language; Human Species	Previous 10 years: 2010-2019	The database contains a broad range of medical topics relating to research, clinical practice, administration, policy issues, and health care services. Produced by the U.S. National Library of Medicine, MEDLINE contains all records published in Index Medicus and since 2002, most citations previously included in separate NLM specialty databases such as SPACELINE and HISTLINE.
4. Mav Scholar Advanced Search (MSAS)	Online / Full Text; English language; Scholarly and Peer-reviewed articles	Previous 10 years: 2010-2019	MSAS database provides citations, abstracts to articles, and full text articles to MSU, Mankato students as a means to easily search across all disciplines.

**Table 2***Data Abstraction Process*

<b>Date of Search</b>	<b>Key Words</b>	<b>Hits in ASP</b>	<b>Hits in CINAHL</b>	<b>Hits in Medline</b>	<b>Hits in MSAS</b>
10-19-19	“young adults” AND “cancer”	880	237	4,611	55,901
	“young adults” AND “cancer” NOT “child”	492	135	3,659	40,230
10-26-19	“young adults” AND “cancer” AND “age-specific”	66	<b>*5</b>	27	2,279
	“young adults” AND “cancer” AND “needs”	138	48	436	48,543
	“AYA” AND “cancer” AND “needs”	60	33	<b>*11</b>	1,243
	“AYA” AND “oncology” AND “needs”	49	<b>*8</b>	<b>*3</b>	854
	“AYA” AND “oncology” AND “needs” AND “age-specific”	*3	*1	0	87
	“young adult” AND “oncology” AND “needs” AND “age-specific”	<b>*5</b>	<b>*1</b>	<b>*16</b>	559
	“young adult” AND “cancer” AND “needs” AND “age-specific”	<b>*6</b>	<b>*4</b>	66	2,004
11-16-19	“young adult” AND “cancer” AND “age-specific needs”	<b>*7</b>	<b>*10</b>	59	2,083
	“young adult” AND “cancer” AND “age-specific needs” AND “quality of care”	X	X	X	<b>*25</b>
	“young adult” AND “cancer” AND “needs” AND “quality of care” AND “outcomes”	<b>*21</b>	34	343	22,080
	“adolescents and young adults with cancer” AND “needs” [search field = title]	<b>*20</b>	<b>*7</b>	X	X

**\*BOLD** = articles reviewed for match with systematic review inclusion criteria    X = not searched in database

**Table 3***Characteristics of Literature Included and Excluded*

<b>Reference</b>	<b>Included/Excluded</b>	<b>Rationale</b>
Barakat, L. P., Galtieri, L. R., Szalda, D., & Schwartz, L. A. (2016). Assessing the psychosocial needs and program preferences of adolescents and young adults with cancer. <i>Supportive Care in Cancer</i> , 24(2), 823-832. <a href="https://doi.org/10.1007/s00520-015-2849-8">https://doi.org/10.1007/s00520-015-2849-8</a>	Excluded	Though the qualitative research done addressed the psychosocial needs and program preferences of AYAs, the mean age of study participants was <18 (17.37). As participants aged 12-17 were included and ages 30-40 were excluded, the study was excluded as this review aimed to primarily explore AYAs aged 18-40.
Bell, J. A., Forcina, V., Mitchell, L., Tam, S., Wang, K., Gupta, A. A., & Lewin, J. (2018). Perceptions of and decision making about clinical trials in adolescent and young adults with cancer: A qualitative analysis. <i>BMC Cancer</i> , 18(1), Article s12885. <a href="https://doi.org/10.1186/s12885-018-4515-2">https://doi.org/10.1186/s12885-018-4515-2</a>	Excluded	Recognized that AYAs have distinct biological, psychosocial, and relations needs but did not explore those needs rather explored factors that influenced the decision-making process when considering clinical trial enrollment.
Clinton-McHarg, T., Carey, M., Sanson-Fisher, R., D'Este, C., & Shakeshaft, A. (2012). Preliminary development and psychometric evaluation of an unmet needs measure for adolescents and young adults with cancer: The Cancer Needs Questionnaire - Young People (CNQ-YP). <i>Health and Quality of Life Outcomes</i> , 10(1), Article 13. <a href="https://doi.org/10.1186/1477-7525-10-13">https://doi.org/10.1186/1477-7525-10-13</a>	Excluded	While the focus of the research in the article was development of a questionnaire to capture the specific unmet needs of the AYA age cohort, it was excluded from the systematic review as it focused more on the questionnaire validity rather than exploration of AYA age-specific needs. It also was excluded as the reliability of the tool was limited by a small sample size of AYA patients.
D'Agostino, N., Penney, A., & Zebrack, B. (2011). Providing developmentally appropriate psychosocial care to adolescent and young adult cancer survivors. <i>Cancer</i> , 117(10 Suppl), 2329-2334. <a href="https://doi.org/10.1002/encr.26043">https://doi.org/10.1002/encr.26043</a>	Included	Specifically addresses the importance of delivering developmentally appropriate psychosocial care to AYAs and emphasizes minimizing the disruption caused by the cancer experience to ultimately maximize health related quality of life for AYAs.
D'Agostino, N., & Edelstein, K. (2013). Psychosocial challenges and resource needs of young adult cancer survivors: Implications for program development. <i>Journal of Psychosocial Oncology</i> , 31(6), 585-600. <a href="https://doi.org/10.1080/07347332.2013.835018">https://doi.org/10.1080/07347332.2013.835018</a>	Excluded	Though participants in the qualitative study were age 18-35, a large portion of the participants were diagnosed in early childhood (approximately age 10). Additionally, the research also focused specifically on long-term cognitive effects of childhood brain tumor survivors which decreases generalizability of research results.
Daniel, C. L., Emmons, K. M., Fasciano, K., Nevidjon, B., Fuemmeler, B., & Demark-Wahnefried, W. (2015). Needs and lifestyle challenges of adolescents and young adults with cancer: Summary of an Institute of Medicine and Livestrong Foundation workshop. <i>Clinical Journal of Oncology Nursing</i> , 675-681. <a href="https://doi.org/10.1188/15.CJON.19-06AP">https://doi.org/10.1188/15.CJON.19-06AP</a>	Included	Summarizes needs and lifestyle challenges of AYAs with cancer, specifically discussing the increased risk of poor diet, low physical activity, and substance abuse. By addressing age-specific needs, quality of care can be enhanced.
DeRouen, M., Smith, A., Tao, L., Bellizzi, K., Lynch, C., Parsons, H., Kent, E. E., & Keegan, T. H. M. (2015). Cancer-related information needs and cancer's impact on control over life influence health-related quality of life among adolescents and young adults with cancer. <i>Psycho-Oncology</i> , 24(9), 1104-1115. <a href="https://doi.org/10.1002/pon.3730">https://doi.org/10.1002/pon.3730</a>	Included	This study was included as it examined the correlation between unmet information needs and health-related quality of life. Also, it had a large sample size of 484 AYA cancer survivors, all of which were in the target age group of 18-39 when filling out the SF-12 HRQOL questions.

Reference	Included/Excluded	Rationale
Epelman, C. (2013). The adolescent and young adult with cancer: State of the art - psychosocial aspects. <i>Current Oncology Reports</i> , 15(4), 325-331. <a href="https://doi.org/10.1007/s11912-013-0324-6">https://doi.org/10.1007/s11912-013-0324-6</a>	Included	Expert opinion in this article recognized AYAs as a distinct subgroup of oncology patients and detailed the unique physical, psychological, and social challenges faced by AYAs which qualified it for inclusion in the systematic review.
Fridgen, O., Sehovic, I., Bowman, M. L., Reed, D., Tamargo, C., Vadaparampil, S., & Quinn, G. (2017). Contraception: The need for expansion of counsel in adolescent and young adult (AYA) cancer care. <i>Journal of Cancer Education</i> , 32(4), 924-932. <a href="https://doi.org/10.1007/s13187-016-1003-8">https://doi.org/10.1007/s13187-016-1003-8</a>	Included	Inclusion criteria for the systematic review was that research must address one or more needs of young adults with cancer. Though this single quantitative study singularly addressed contraception counseling, it detailed the importance of this frequently overlooked aspect of young adult cancer care.
Galán, S., De La Vega, R., & Miró, J. (2016). Needs of adolescents and young adults after cancer treatment: A systematic review. <i>European Journal of Cancer Care</i> , 27(6), Article e12558. <a href="https://doi.org/10.1111/ecc.12558">https://doi.org/10.1111/ecc.12558</a>	Included	Not only did this article specifically address the clinical research question of the needs of AYAs, it was included as authors applied rigorous analysis of 14 studies in this systematic review.
Gupta, A. A., Edelstein, K., Albert-Green, A., & D'Agostino, N. (2013). Assessing information and service needs of young adults with cancer at a single institution: The importance of information on cancer diagnosis, fertility preservation, diet, and exercise. <i>Supportive Care in Cancer</i> , 21(9), 2477-2484. <a href="https://doi.org/10.1007/s00520-013-1809-4">https://doi.org/10.1007/s00520-013-1809-4</a>	Included	Quantitative research study that highlights supportive care preferences and needs of AYAs and emphasizes the development of AYA programs that focuses on those needs to improve quality of life, psychosocial adjustment, and improve other outcomes during and after cancer treatment.
Gupta, A. A., Papadakos, J. K., Jones, J. M., Amin, L., Chang, E. K., Korenblum, C., Mina, D. S., McCabe, L., Mitchell, L., & Giuliani, M. E. (2016). Reimagining care for adolescent and young adult cancer programs: Moving with the times. <i>Cancer</i> , 122, 1038-1046. <a href="https://doi.org/10.1002/cncr.29834">https://doi.org/10.1002/cncr.29834</a>	Included	This article meets inclusion criteria as it specifically addresses AYA needs. However, it goes a step further by providing expert opinion on idealistic AYA program strategies to address each comprehensive AYA need.
Hydeman, J. A., Uwazurike, O. C., Adeyemi, E. I., & Beaupin, L. K. (2019). Survivorship needs of adolescent and young adult cancer survivors: A concept mapping analysis. <i>Journal of Cancer Survivorship</i> , 13(1), 34-42. <a href="https://doi.org/10.1007/s11764-018-0725-5">https://doi.org/10.1007/s11764-018-0725-5</a>	Included	This study is valuable as it was recently published (January 2019) and innovatively used a concept mapping design based on AYA study participants' statements of principal issues during their transition to survivorship.
Keegan, T., Lichtensztajn, D., Kato, I., Kent, E., Wu, X., West, M., Hamilton, A. S., Zebrack, B., Bellizzi, K. M., & Smith, A. (2012). Unmet adolescent and young adult cancer survivors information and service needs: A population-based cancer registry study. <i>Journal of Cancer Survivorship</i> , 6(3), 239-250. <a href="https://doi.org/10.1007/s11764-012-0219-9">https://doi.org/10.1007/s11764-012-0219-9</a>	Included	Study results specifically address this systematic review's clinical research question by identifying unmet information and service needs. This study was included for its large sample size, gathering information from 523 AYA cancer survivors who completed the Adolescent and Young Adult Health Outcomes and Patient Experience [AYA HOPE] survey.
Landwehr, M. S., Watson, S. E., Macpherson, C. F., Novak, K. A., & Johnson, R. H. (2016). The cost of cancer: A retrospective analysis of the financial impact of cancer on young adults. <i>Cancer Medicine</i> , 5(5), 863-870. <a href="https://doi.org/10.1002/cam4.657">https://doi.org/10.1002/cam4.657</a>	Included	Inclusion criteria for the systematic review was that research must address one or more needs of young adults with cancer. Though this single quantitative study addressed only the financial toxicity experienced by the target population, it was a thorough and compressive analysis of the financial impact that a cancer diagnosis has on young adults.

Reference	Included/Excluded	Rationale
Lie, N., Larsen, T., & Hauken, M. (2018). Coping with changes and uncertainty: A qualitative study of young adult cancer patients' challenges and coping strategies during treatment. <i>European Journal of Cancer Care</i> , 27(6), Article e12743. <a href="https://doi.org/10.1111/ecc.12743">https://doi.org/10.1111/ecc.12743</a>	Excluded	While this qualitative study was specific to the population of young adults with cancer, it was excluded on the basis of its focus not on patient needs but rather challenges and coping strategies experienced during treatment.
Mitchell, L., Tarn, S., & Gupta, A. A. (2018). Crucial conversations: Addressing informational needs of adolescents and young adults diagnosed with cancer. <i>Clinical Journal of Oncology Nursing</i> , 22(5), 483-486. <a href="https://doi.org/10.1188/18.CJON.483-486">https://doi.org/10.1188/18.CJON.483-486</a>	Excluded	Though the article highlighted how a cancer diagnosis is experienced differently in the AYA population, it's rigor as a brief expert opinion article was questionable. Additionally, it focused more on discussion of the critical time points that AYAs have needs and less on substantive discussion of what those needs are.
Nass, S., Beupin, L., Demark-Wahnefried, W., Fasciano, K., Ganz, P., Hayes-Lattin, B., Hudson, M. M., Nevidjon, B., Oeffinger, K. C., Rechis, R., Richardson, L. C., Seibel, N. L., & Smith, A. (2015). Identifying and addressing the needs of adolescents and young adults with cancer: Summary of an Institute of Medicine Workshop. <i>The Oncologist</i> , 20(2), 186-195. <a href="https://doi.org/10.1634/theoncologist.2014-0265">https://doi.org/10.1634/theoncologist.2014-0265</a>	Included	The Institute of Medicine, now known as the National Academy of Medicine, is a well-known and reputable organization that provides unbiased, evidenced-based health information. The article summarized various AYA needs as well as provided suggestions to improve quality of AYA care and outcomes.
Pannier, S. T., Warner, E. L., Fowler, B., Fair, D., Salmon, S. K., & Kirchhoff, A. C. (2019). Age-specific patient navigation preferences among adolescents and young adults with cancer. <i>Journal of Cancer Education</i> , 34(2), 242-251. <a href="https://doi.org/10.1007/s13187-017-1294-4">https://doi.org/10.1007/s13187-017-1294-4</a>	Excluded	Although this quantitative study was specific to AYAs with cancer, it was excluded on the foundation that its emphasis was not on patient needs but instead on age-specific patient navigation preferences.
Ricadat, É., Schwering, K., Fradkin, S., Boissel, N., & Aujoulat, I. (2019). Adolescents and young adults with cancer: How multidisciplinary health care teams adapt their practices to better meet their specific needs. <i>Psycho-Oncology</i> , 28(7), 1576-1582. <a href="https://doi.org/10.1002/pon.5135">https://doi.org/10.1002/pon.5135</a>	Excluded	The article was excluded as it focused more on the perceptions of healthcare professionals and less on the patient perspective of AYA needs. Research was also limited to AYA-dedicated hospital units, which represents only one portion of the care continuum.
Warner, E. L., Kent, E. E., Trevino, K. M., Parsons, H. M., Zebrack, B. J., & Kirchhoff, A. C. (2016). Social well-being among adolescents and young adults with cancer: A systematic review. <i>Cancer</i> , 122(7), 1029-1037. <a href="https://doi.org/10.1002/cncr.29866">https://doi.org/10.1002/cncr.29866</a>	Included	Included due to its rigor as a systematic review that analyzed 26 articles and identified domains of social well-being that are understudied in the AYA population.
Zebrack, B., Mathews-Bradshaw, B., & Siegel, S. (2010). Quality cancer care for adolescents and young adults: A position statement. <i>Journal of Clinical Oncology</i> , 28(32), 4862-4867. <a href="https://doi.org/10.1200/JCO.2010.30.5417">https://doi.org/10.1200/JCO.2010.30.5417</a>	Included	Position statement from Livestrong that outlines necessary personnel, components, and services of AYA care across the continuum - diagnosis, treatment, survivorship, and end of life.
Zebrack, B., Block, R., Hayes-Lattin, B., Embry, L., Aguilar, C., Meeske, K., Li, Y., Butler, M., & Cole, S. (2013). Psychosocial service use and unmet need among recently diagnosed adolescent and young adult cancer patients. <i>Cancer</i> , 119(1), 201-214. <a href="https://doi.org/10.1002/cncr.27713">https://doi.org/10.1002/cncr.27713</a>	Included	Discussed service uses and unmet needs of YA patients recently diagnosed with cancer. Provides insight into how even the age differences among the AYA population impacts what services are needed at specific ages and developmental stages.
Zebrack, B., Corbett, V., Embry, L., Aguilar, C., Meeske, K., Hayes-Lattin, B., Block, R., Zeman, D. T., & Cole, S. (2014). Psychological distress and unsatisfied need for psychosocial support in adolescent and young adult cancer patients during the first year following diagnosis. <i>Psycho-Oncology</i> , 23(11), 1267-1275. <a href="https://doi.org/10.1002/pon.3533">https://doi.org/10.1002/pon.3533</a>	Included	Similar to other included articles, this research study examines psychological distress and unsatisfied need for psychosocial support. What is unique about this study is that it focuses specifically on the first year following a cancer diagnosis.

**Table 4***Literature Review Table of All Studies Included*

Citation	Study Purpose	Pop (N) / Sample (n) / AYA age range	Level of Evidence / Design	Research methods, tools (surveys, etc.), or Intervention	Findings / Themes	Implications
D'Agostino, N., Penney, A., & Zebrack, B. (2011). Providing developmentally appropriate psychosocial care to adolescent and young adult cancer survivors. <i>Cancer, 117</i> (10 Suppl), 2329-2334. <a href="https://doi.org/10.1002/cncr.26043">https://doi.org/10.1002/cncr.26043</a>	Commentary / opinion that focuses on how to address the health care needs of AYA patients	N/A 15-29	Level VII Evidence from the opinion of authorities	AYA workshop participants suggested features of developmentally appropriate AYA psychosocial care	Critical elements of effective AYA psychosocial services: - Access to AYA-specific information & support resources - Fertility and sexuality counseling - Programs to maximize academic and vocational functioning - Financial support	By being aware of the critical elements of effective AYA psychosocial care and using a flexible interaction style and approach, healthcare professionals can help achieve the ultimate goal of supporting AYAs with cancer, which is facilitating their achievement as self-reliant, independent, and productive members of society.
Daniel, C. L., Emmons, K. M., Fasciano, K., Nevidjon, B., Fuemmeler, B., & Demark-Wahnefried, W. (2015). Needs and lifestyle challenges of adolescents and young adults with cancer: Summary of an Institute of Medicine and Livestrong Foundation workshop. <i>Clinical Journal of Oncology Nursing, 6</i> 75-681. <a href="https://doi.org/10.1188/15.CJON.19-06AP">https://doi.org/10.1188/15.CJON.19-06AP</a>	Commentary / opinion to raise awareness of AYAs lifestyle challenges and recommend future directions	N/A 15-39	Level VII Report of Expert Committee (Institute of Medicine and Livestrong Foundation)	Workshop participants addressed AYA survivor needs	Lifestyle challenges: - Poor diet - Low physical activity (PA) - Substance abuse	AYAs develop socially, emotionally, and cognitively at unique rates. Consequently, healthcare professionals need to understand AYA lifestyle challenges and developmental differences to foster health-promoting behaviors and advocate for specialty referral as needed.
DeRouen, M., Smith, A., Tao, L., Bellizzi, K., Lynch, C., Parsons, H., Kent, E. E., & Keegan, T. H. M. (2015). Cancer-related information needs and cancer's impact on control over life influence health-related quality of life among adolescents and young adults with cancer. <i>Psycho-Oncology, 24</i> (9), 1104-1115. <a href="https://doi.org/10.1002/pon.3730">https://doi.org/10.1002/pon.3730</a>	Examine whether unmet information need and perceived control over life are associated with health-related quality of life (HRQOL)	n = 484 18-39	Level IV Evidence from a single quantitative study	Short-form 12 HRQOL questions from the AYA HOPE survey	AYA patients with cancer have elevated levels of unmet cancer-related information needs and perceived negative impact of cancer on control over life. Both are associated with lower HRQOL.	Providing relevant health information across the AYA age spectrum is important. There is a need for developmentally appropriate interventions to increase AYAs' understanding of topics related to cancer and cancer treatment. By addressing needs and increasing sense of control, healthcare professionals may be able to improve HRQOL in the YA population.
Epelman, C. (2013). The adolescent and young adult with cancer: State of the art - psychosocial aspects. <i>Current Oncology Reports, 15</i> (4), 325-331. <a href="https://doi.org/10.1007/s11912-013-0324-6">https://doi.org/10.1007/s11912-013-0324-6</a>	Commentary / opinion discussing the unique physical, psychological, and social challenges faced by AYAs	N/A	Level VII Expert opinion	N/A	AYA developmental milestones: - Developing identity and values - Independence from parents - Financial/social autonomy Unique needs: - Promote adherence/compliance - Peer group interaction - Address body image, sexuality, & fertility - Address substance use - Education/employment assistance - Advise on late effects of cancer	Healthcare professionals should receive specialized training to support AYAs with cancer and address their specific physical, psychological, and social needs. Improved communication and flexibility will help to promote treatment adherence and compliance as it relates to health-seeking behaviors.

Citation	Study Purpose	Pop (N) / Sample (n) / AYA age range	Level of Evidence / Design	Research methods, tools (surveys, etc.), or Intervention	Findings / Themes	Implications
Fridgen, O., Sehovic, I., Bowman, M. L., Reed, D., Tamargo, C., Vadaparampil, S., & Quinn, G. (2017). Contraception: The need for expansion of counsel in adolescent and young adult (AYA) cancer care. <i>Journal of Cancer Education</i> , 32(4), 924-932. <a href="https://doi.org/10.1007/s13187-016-1003-8">https://doi.org/10.1007/s13187-016-1003-8</a>	Examine available literature on contraception recommendations and counseling	5 articles 15-45	Level V Systematic Review of 5 quantitative studies	Three reviewers used the 'Quality Assessment Tool for Quantitative Studies' to appraise each article	HCPs must be flexible in their approach to contraception counseling as various methods are available and AYAs have individualized needs based on their specific cancer, treatment, and future childbearing goals.	It is recommended that HCPs who care for AYAs with cancer identify future family goals, discuss types and efficacy of contraception, dispel myths about infertility, and include necessary partners in the conversations.
Galán, S., De La Vega, R., & Miró, J. (2016). Needs of adolescents and young adults after cancer treatment: A systematic review. <i>European Journal of Cancer Care</i> , 27(6), Article e12558. <a href="https://doi.org/10.1111/ecc.12558">https://doi.org/10.1111/ecc.12558</a>	Conduct a systematic review of the literature on the needs of AYAs who have survived cancer	14 articles 14-39	Level V Mixed Methods Systematic Review of 14 studies	Two researchers used a checklist to assess qualitative and quantitative studies	Common AYA survivor needs: - Individualized information and advice (adapted healthcare, relapse detection, healthy lifestyle) - Counseling and psychological support (back to normal life & adaptation to new role) - Social support and social relationships (financial support)	Highlights the importance of reaching a consensus among healthcare professionals (HCPs) regarding how AYA survivors' needs should be conceptualized and reliable procedures for assessing those AYA patient needs. Over time, AYA needs shift and it is the HCPs duty to help bring AYAs back to their normal life.
Gupta, A. A., Edelstein, K., Albert-Green, A., & D'Agostino, N. (2013). Assessing information and service needs of young adults with cancer at a single institution: The importance of information on cancer diagnosis, fertility preservation, diet, and exercise. <i>Supportive Care in Cancer</i> , 21(9), 2477-2484. <a href="https://doi.org/10.1007/s00520-013-1809-4">https://doi.org/10.1007/s00520-013-1809-4</a>	Identify information and service needs important to YA cancer patients	n = 243 18-35	Level IV Evidence from a single quantitative study	Questionnaire (cancer needs questionnaire with 17 needs)	Highest ranked needs: - Information on specific malignancy - Fertility effects of treatment - Maintaining a healthy diet - Physical fitness during treatment	By identifying needs of AYA patients with cancer, healthcare organizations can accurately inform development of a dedicated AYA program. Programs can then lessen distress, improve the cancer experience, and empower AYAs on their cancer journey.
Gupta, A. A., Papadakis, J. K., Jones, J. M., Amin, L., Chang, E. K., Korenblum, C., Mina, D. S., McCabe, L., Mitchell, L., & Giuliani, M. E. (2016). Reimagining care for adolescent and young adult cancer programs: Moving with the times. <i>Cancer</i> , 122, 1038-1046. <a href="https://doi.org/10.1002/cncr.29834">https://doi.org/10.1002/cncr.29834</a>	Commentary / opinion to assist other healthcare organizations in expanding existing services to address the needs of AYA patients with cancer	N/A <39	Level VII Expert opinion	Commentary from experts at a single large urban adult cancer center in Canada	AYA comprehensive needs domains: - Symptom management (sexuality, fatigue) - Behavior modification (return to work, exercise) - Health services (advanced cancer and survivorship)	Through advisement from a comprehensive cancer center that cares for over 1300 new AYAs per year, other healthcare organizations can identify what unique services are important to meeting the comprehensive needs of AYAs. It is important to leverage outside services and expertise including external and philanthropic funding for AYA program success.
Hydeman, J. A., Uwazurike, O. C., Adeyemi, E. I., & Beaupin, L. K. (2019). Survivorship needs of adolescent and young adult cancer survivors: A concept mapping analysis. <i>Journal of Cancer Survivorship</i> , 13(1), 34-42. <a href="https://doi.org/10.1007/s11764-018-0725-5">https://doi.org/10.1007/s11764-018-0725-5</a>	Focus groups were conducted to better understand the most prominent issues AYAs face when transitioning to survivorship	n = 27 Diagnosed between 18-39	Level VI Evidence from a single qualitative study	Focus group prompt statement: "List the issues that made transition from active treatment to survivorship difficult for you." Concept mapping framework	Themes that emerged when AYAs were asked about issues that made transition to survivorship difficult: - Adjusting to a new normal - Developing a new identity - Navigating relationships - Navigating cancer care after treatment - Issues related to follow-up care - Ongoing physical effects - Cognitive effects of treatment	AYA survivors have unaddressed concerns as they transition out of active cancer treatment that are based on individualized developmental trajectories. Communication with healthcare professionals and formulation of survivorship care plans would benefit AYAs in addressing their unique concerns.



Citation	Study Purpose	Pop (N) / Sample (n) / AYA age range	Level of Evidence / Design	Research methods, tools (surveys, etc.), or Intervention	Findings / Themes	Implications
Keegan, T., Lichtensztajn, D., Kato, I., Kent, E., Wu, X., West, M., Hamilton, A. S., Zebrack, B., Bellizzi, K. M., & Smith, A. (2012). Unmet adolescent and young adult cancer survivors information and service needs: A population-based cancer registry study. <i>Journal of Cancer Survivorship</i> , 6(3), 239-250. <a href="https://doi.org/10.1007/s11764-012-0219-9">https://doi.org/10.1007/s11764-012-0219-9</a>	Describe the unmet information and services needs of adolescent and young adult (AYA) cancer survivors and identify socio-demographic and health-related factors associated with those unmet needs	n = 523 15-39	Level IV Evidence from a single quantitative study	Adolescent and Young Adult Health Outcomes and Patient Experience [AYA HOPE] survey	Unmet information needs: (>50% reported unmet) - Cancer recurrence - Cancer treatment - Long-term side effects - Complementary/alternative treatments (25-50% reported unmet) - Physical fitness - Meeting other AYAs - Nutrition / diet - Financial support - Risk of family getting cancer Unmet service needs: - Mental health care professional - In-home nursing care - Support group	The large study highlighted the various information and service needs that are not being met among AYA cancer survivors. Those survivors with more physical and emotional symptoms report more unmet needs. Unmet needs also vary by demographic and health-related factors. Additionally, information and service needs change throughout the survivorship continuum.
Landwehr, M. S., Watson, S. E., Macpherson, C. F., Novak, K. A., & Johnson, R. H. (2016). The cost of cancer: A retrospective analysis of the financial impact of cancer on young adults. <i>Cancer Medicine</i> , 5(5), 863-870. <a href="https://doi.org/10.1002/cam4.657">https://doi.org/10.1002/cam4.657</a>	Retrospectively analyze the financial impact of cancer on young adults	n = 334 19-39	Level IV Evidence from a single quantitative study	Retrospective analysis of the financial status of grant recipients	Overall, financial indicators of YA cancer survivors are worse in many domains as compared to age-matched controls. Financial challenges included: - Lower median income - Higher out-of-pocket expenses - Lower net worth - Higher medical debt - Missed career opportunities	This study highlights the significance of the devastating and age-specific impact of cancer on the finances of young adults. Since young adult cancer survivors with financial concerns report increased levels of depression, stress, and anxiety, addressing this need is important to patient outcomes.
Nass, S., Beupin, L., Demark-Wahnefried, W., Fasciano, K., Ganz, P., Hayes-Lattin, B., Hudson, M. M., Nevidjon, B., Oeffinger, K. C., Rechis, R., Richardson, L. C., Seibel, N. L., & Smith, A. (2015). Identifying and addressing the needs of adolescents and young adults with cancer: Summary of an Institute of Medicine Workshop. <i>The Oncologist</i> , 20(2), 186-195. <a href="https://doi.org/10.1634/theoncologist.2014-0265">https://doi.org/10.1634/theoncologist.2014-0265</a>	Commentary / opinion that highlights potential action items to improve the care and outcomes for AYA patients with cancer	N/A 15-39	Level VII Report of Expert Committee (Institute of Medicine)	Workshop participants identified gaps in AYA care and suggested strategies to address their needs	Gaps in care: - Preserving fertility - Psychosocial aspects - Palliative Care - Late/Long-term effects - Lifelong survivorship care - End-of-life care	Gaps in the evidence base to support AYAs with cancer need to be addressed and research needs to fill those gaps. Future needs include programs to educate healthcare professionals who care for AYAs and facilitation of AYA participation in research/clinical trials.
Warner, E. L., Kent, E. E., Trevino, K. M., Parsons, H. M., Zebrack, B. J., & Kirchhoff, A. C. (2016). Social well-being among adolescents and young adults with cancer: A systematic review. <i>Cancer</i> , 122(7), 1029-1037. <a href="https://doi.org/10.1002/cncr.29866">https://doi.org/10.1002/cncr.29866</a>	Identify the domains of social well-being that are understudied in the AYA population	26 articles 15-39	Level V Mixed Methods Systematic Review of 26 articles	Three researchers used a standardized template to appraise studies	AYAs report difficulty with: - Employment - Educational attainment - Financial stability - Maintenance/development of peer and family relationships - Intimate/marital relationships - Peer support - Supportive services	By identifying the domains of social well-being that are understudied in the AYA population, healthcare professionals recognize priority areas for intervention. HCPs need to prioritize the areas of education, employment, and social support networks.

Citation	Study Purpose	Pop (N) / Sample (n) / AYA age range	Level of Evidence / Design	Research methods, tools (surveys, etc.), or Intervention	Findings / Themes	Implications
Zebrack, B., Mathews-Bradshaw, B., & Siegel, S. (2010). Quality cancer care for adolescents and young adults: A position statement. <i>Journal of Clinical Oncology</i> , 28(32), 4862-4867. <a href="https://doi.org/10.1200/JCO.2010.30.5417">https://doi.org/10.1200/JCO.2010.30.5417</a>	Dissemination of a position statement to raise awareness of the need for AYA-specific care guidelines	N/A 20-39	Level VII Report of Expert Committee (Young Adult Oncology Process Review Group)	Experts derived a position statement for quality AYA care	Quality AYA care depends on: - Timely detection - Efficient diagnosis processes - Treatment initiation - Promotion of adherence - Cognizance of unique psychosocial AYA context - Age-appropriate information and support services	Since the AYA patient population has distinct needs, formulating and disseminating recommendations for care will raise awareness for age-specific needs which will assist providers in the delivery of care.
Zebrack, B., Block, R., Hayes-Lattin, B., Embry, L., Aguilar, C., Meeske, K., Li, Y., Butler, M., & Cole, S. (2013). Psychosocial service use and unmet need among recently diagnosed adolescent and young adult cancer patients. <i>Cancer</i> , 119(1), 201–214. <a href="https://doi.org/10.1002/cncr.27713">https://doi.org/10.1002/cncr.27713</a>	Examined the extent to which AYAs treated in pediatric or adult oncology settings reported use of, and unmet need for, psychosocial support services	n =228 14-39	Level IV Evidence from a single quantitative study	Survey completion	Compared to 30-39-year-old patients, YAs 20-29 were more likely to report unmet needs of: - Cancer information - Infertility information - Diet/nutrition information YAs treated in adult settings were more likely to report an unmet need for age-appropriate: - Internet sites - Mental health services - Camp/retreat programs - Transportation assistance - Complementary health services	A substantial portion of AYAs with cancer have unmet psychosocial care needs. By increasing psychosocial support staff and patient referral to community-based social service agencies as well as reputable internet resources, healthcare professionals can enhance quality of life and improve care for AYAs.
Zebrack, B., Corbett, V., Embry, L., Aguilar, C., Meeske, K., Hayes-Lattin, B., Block, R., Zeman, D. T., & Cole, S. (2014). Psychological distress and unsatisfied need for psychosocial support in adolescent and young adult cancer patients during the first year following diagnosis. <i>Psycho-Oncology</i> , 23(11), 1267-1275. <a href="https://doi.org/10.1002/pon.3533">https://doi.org/10.1002/pon.3533</a>	Identify trajectories of clinically significant levels of distress in the first year following diagnosis and distinguish factors that predict the extent of AYA distress	n = 286 15-39	Level IV Evidence from a single quantitative study	Survey completion	Substantial proportion of AYAs reported the need for: - Information - Counseling - Practical support Not getting counseling needs met, especially professional mental health services, was significantly associated with distress over time.	This study highlights the importance of identifying psychologically distressed AYAs. Since many in the AYA population are not utilizing professional psychosocial support services, healthcare professionals need to find innovative ways to address their psychosocial needs throughout the continuum of care.

Melnik, B. M., & Fineout-Overholt, E. (2019). *Evidence-based practice in nursing & healthcare: A guide to best practice* (4<sup>th</sup> ed.).

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Table 5

*Physical, Psychosocial, and Information Needs of YA Cancer Patients*

	Author Year	DAgostino et al., 2011	Daniel et al., 2015	DeRouen et al., 2015	Epelman, 2013	Fridgen et al., 2017	Galan et al., 2016	Gupta et al., 2013	Gupta et al., 2016	Hydeman et al., 2019	Keegan et al., 2012	Landwehr et al., 2016	Nass et al., 2015	Warner et al., 2015	Zebrack et al., 2010	Zebrack et al., 2013	Zebrack et al., 2014
<b>YA Needs</b>																	
<b>Physical Needs</b>																	
- Physical Activity			X	x			x	X	X	x	x		x		x	x	
- Diet / Nutrition			X	x			x	X			x		x		x	x	
- Fertility Preservation		X		x	x	x	x	X		X	x	x	X	x	x	x	
- Contraception						X											
<b>Psychosocial Needs</b>																	
- Mental Health / Counseling		x	x	x	x		x	x		x	x	x	x	x	x	X	X
+ Substance Abuse		x	X		x		x	x					x		x		
- Peer Relationships		X	x	x	X		X	x		x	x		x	X	x	x	x
+ YA Connection		X		x	X		x	x			x		x	x	x	x	x
- Family Relationships		x		x	x		x			x	x		x	x	x	x	x
+ Parenting / Pregnancy				x	x		x				x		x		x		
- Intimate Relations / Sexuality		x		x	x	x	x		X		x		x	x	x		
- Education		X		x	x		x	x			x	x	x	X	x	x	x
- Employment		X		x	x		x	x	X	x	x	x	x	X	x	x	x
- Financial Support		X		x	x		x			X	x	X	x	X	x	x	x
<b>Informational Needs</b>																	
- Individual Cancer Information		X		X		x	X	X	X	x	X		x	X	x	X	X
+ Side Effects			x	x	x	x	x			x	x		X		x		
+ Adherence					x	x	x			x		x	x		x	x	
- Technology / Social Media		x	x				x	x					x	x	x	X	
- CAM				x			x	x			x					x	
- Clinical Trial Enrollment				x	x						x		x		x		
- Survivorship / Follow-Up Care		x		x	x		X		X	X	x	x	X		x		
- Palliative / End of Life Care					x				X				X		x		
<b>X = main topic</b>																	
<b>x = addressed topic</b>																	

