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Treatment of Anxiety and Depression in Adolescents and Young Adults With Cancer

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Abstract

Adolescents and young adults (AYAs) with cancer are a unique population of patients who experience a period of intense and dramatic life changes when they are diagnosed. Overall, AYAs with cancer are resilient; however, their psychosocial needs are often underestimated or unmet. Currently, there are inconsistencies in how AYAs are screened and treated for anxiety and depression. Barriers to treatment include clinicians’ lack of confidence in distinguishing between side effects of treatment and depression/anxiety. Additional barriers include the black box warning for prescribing antidepressants and difficulty partnering with mental health professionals. This article seeks to provide recommendations for pediatric oncology clinicians on how to identify and address anxiety and depression in AYAs and how to partner with mental health professionals in their treatment, and it suggests directions for future research.

Keywords

pediatric oncology, AYA, cancer, psychosocial issues, anxiety and depression

Introduction

The incidence of cancer in adolescents and young adults (AYAs) has steadily increased over the past 25 years. In 2010, an estimated 24,000 people in the United States between the ages of 15 and 29 years were diagnosed with cancer (Centers for Disease Control and Prevention [CDC], 2010). The most recently collected data from the CDC indicate that cancer in this age group is more than 2.5 times more common than cancer in children younger than 15 years. Cancer is also the leading cause of natural death in this age group (Smith et al., 2013). AYAs represent a unique population of patients within oncology. They are in the midst of numerous transitions and are striving to achieve many complex developmental milestones (Epelman, 2013). Being diagnosed with cancer during this time can greatly disrupt their lives and cause a host of psychosocial issues. Although AYAs with cancer are resilient, they are faced with multiple challenges when it comes to dealing with disease and treatment-related effects and adjusting to their illness (Kurtz & Abrams, 2011).

Traditionally, cancer care has been divided into “adult” and “pediatric” without a distinction for AYAs. These patients frequently are seen in pediatric settings, as outcomes are generally better when AYAs with “pediatric-type” cancers are treated with pediatric protocols (Coccia et al., 2012). For example, differences in survival outcomes for patients with acute lymphoblastic leukemia have been observed, favoring AYA patients who are treated with pediatric protocols as opposed to adult protocols (Zebrack et al., 2013). There has been a relative lack of improvement in outcomes in AYA patients with cancer, one of the reasons being low rates of clinical trial participation. Pediatric centers enroll far more AYAs in clinical trials (35% vs 12% at nonpediatric centers).

Depression and anxiety are common in adolescence and young adulthood and are particularly relevant in AYAs with cancer. Symptoms of anxiety and depression can affect quality of life and treatment adherence. Additionally, physical symptoms related to depression can sometimes cause alteration of treatment such as lowering of chemotherapy doses, blood product transfusions, and frequency of follow-up (Kersun, Rourke, Mickley, & Kazak, 2009). Many studies have explored quality of life and psychosocial issues among children and adult survivors of childhood cancer; however, less is known about
patients diagnosed with cancer during adolescence or young adulthood. Little is known about the negative and positive psychosocial impacts of being diagnosed with cancer at such a tumultuous time. The few studies that have examined AYAs have demonstrated significant psychosocial effects (Bellizzi et al., 2012).

Currently, the literature reports conflicting data regarding the extent of anxiety and depression in AYAs being treated for cancer. Articles published by Kurtz and Abrams (2011) and Phipps et al. (2012) state that most children with cancer do not exhibit higher levels of anxiety and depression than population norms. Conversely, the 2013 AYA HOPE study conducted by Smith et al. concluded that AYA patients with cancer have significantly worse health-related quality of life (HRQL) than population norms. Disparities were seen in social functioning, limitations in emotional roles, and mental health. A 2013 study by Zebrack et al. found a growing body of literature affirming that psychosocial issues for AYAs are distinct from those of both pediatric and older adult populations and that AYA oncology patients may not be served sufficiently by existing services.

This article seeks to review the literature surrounding the incidence of depression and other psychosocial effects in AYA cancer patients and to provide recommendations for pediatric oncology clinicians on how to identify and address anxiety and depression in AYAs and how to best use mental health resources.

### AYA Development

There are some inconsistencies in defining what ages “AYA” includes. Some define it as 15 to 39 years, but most literature (and this article) use 15 to 29 years. According to developmental theorist Erik Erikson’s (1963) stages of development, 2 important phases occur during this time (see Table 1). Adolescence (ages 12-18) involves struggling to find one’s own identity while negotiating social interactions and figuring out how to “fit in.” The emphasis is on autonomy, developing a sense of self, and sexuality, and this phase has potential for major growth or crisis. Adolescents are grappling with hormonal changes, increasing cognitive ability, uncertainty, self-consciousness, emotional lability, and increases in risk-taking behavior (Thompson, Dyson, Holland, & Joubert, 2013). In the young adulthood stage (ages 19-35), the goal is finding a partner and the focus is on building and maintaining intimate relationships. Many young adults may marry during this time, start families, and develop careers. If they are unsuccessful in this stage, isolation and loneliness may occur.

Accompanying these numerous developmental changes are practical transitions, including increasing autonomy both personally and financially, evolving relationships, and changes in school and work settings (Smith et al., 2013). AYAs may be independently navigating diagnosis, treatment, and health care decisions. For those with a life-threatening illness, achieving these developmental milestones can be extremely difficult. The diagnosis of cancer may lead to increased dependence on caregivers, requirement to conform to the values and beliefs of caregivers, and social isolation (Epelman, 2013). These AYAs struggle with the need for independence, which is in direct conflict with the need to have someone take care of them. The demands of the diagnosis disrupt adolescents’ ability to exercise independence and bond with their peer group. They often miss out on experiences that their peers are enjoying, and they feel left behind. Treatment for many patients can last longer than 1 year, which disrupts their ability to make plans for the future (Morgan, Davies, Palmer, & Plaster, 2010).

Cognitively, adolescents are able to think abstractly and can understand the complexity of a chronic illness in the same way as adults. Adolescents can comprehend the impact of a life-threatening or chronic illness but are not always prepared to manage the changes in their lifestyle and activities that the treatment demands (Kurtz & Abrams, 2011). Even if adolescents fully understand their disease and prognosis, they may not have developed healthy mechanisms to cope with the anxiety and sadness that occur with such a serious diagnosis.

### Anxiety and Depression

Data regarding the true incidence of anxiety and depression in AYAs undergoing treatment for cancer are conflicting.
Difficulty in identifying anxiety and depression is a theme in the literature, and relatively few studies have examined AYAs currently undergoing treatment. Many clinicians assume that feelings of depression and anxiety are normal responses when patients are undergoing cancer treatment and therefore may overlook some worrisome symptoms of anxiety and depression (Kersun et al., 2009). Many common symptoms of depression overlap with symptoms of cancer (anhedonia, sleep and appetite disturbances, lethargy, difficulty concentrating), and it may be difficult to distinguish the cause. A study evaluating pediatric oncology staff assessment of depression and anxiety in adolescent cancer patient found that staff could reasonably identify adolescents with anxiety but not those with depression (Hedstrom, Kreuger, Ljungman, Nygren, & von Essen, 2006). While quick screening tools for depression and anxiety exist, it is unclear whether the measures used for the general population are adequate to use in oncology patients given the need to differentiate the cause of the symptoms (Phipps et al., 2012). Even more specific screening methods such as the Psychosocial Assessment Tool (Kazak et al., 2011), which is routinely used to assess family distress in pediatric oncology, has not been validated for use in AYAs with cancer.

The language that is used in studies is inconsistent. Often, “distress” is measured, making it difficult to tease out what is true depression or anxiety. Dyson, Thompson, Palmer, Thomas, and Schofield (2011) examined the rates and types of distress experienced by teenagers 4 to 8 weeks after they were diagnosed with cancer. The main types included physical concerns (nausea, mucositis), personal changes (hair loss, fatigue, and weight changes) and treatment-related worries (missing school and missing social activities). The study concluded that these anxieties caused AYAs significant distress. Another recent study showed the frequency of children exhibiting symptoms that were consistent with both depression and anxiety. The same study showed that anxiety and depression scores at 1 month after diagnosis significantly predicted persistence of symptoms throughout the first year of therapy (Myers et al., 2014).

Several studies have identified risk factors for those AYAs who have an increased likelihood of experiencing distress with a diagnosis of cancer. Impaired parental coping is a predictor of compromised coping in patients. Having social or emotional issues prior to diagnosis or preexisting developmental and social deficits has been shown to predict psychological problems after diagnosis (Abrams, Hazen, & Penson, 2007). Rates of anxiety and depression vary among different diagnoses, and the type of cancer may play a role in the psychological effect on the AYA patient. For example, children with brain tumors are likely to experience more psychological distress (Kurtz and Abrams, 2011).

Many studies have looked at adult oncology patients. In adults, depression occurs in 15% of the general population, and rates of depression in adults with cancer are 2 to 3 times greater than in the general population (Fisch, 2004). Studies of adult patients of all ages indicate significantly higher rates of distress among young adult cancer patients when compared with older adult patients. In adult oncology patients with depression, antidepressant therapy and psychotherapy seem to be equally effective for treating mild to moderate depression.

Depression and anxiety have many consequences in this population. They are both common complications of experiencing acute and chronic pain. Because pain in chronic disease cannot always be anticipated (as opposed to postoperative pain), it is commonly underassessed and undertreated (Apter, Farbstein, & Yaniv, 2003). Treatment-related anticipatory anxiety with nausea and vomiting is fairly common. Depression is associated with disease morbidity, increased length of hospital stays, and readmissions. It may cause impairments in cognitive function, damaged social relationships, suicidal ideation, and violence (Portteus, Ahmad, Tobey, & Leavy, 2006). These patients are more prone to substance abuse (Szalda, Brumley, Danielson, & Schwartz, 2013), which is especially dangerous while in treatment. Depression is correlated with treatment nonadherence (Portteus et al., 2006), which can have devastating ramifications including reduced treatment efficacy and increased risk of relapse. Untreated depression may also impair the immune system and delay healing and recovery (Apter et al., 2003). It is important to routinely screen for these issues in order to facilitate interventions early in treatment.

**Treatment for Anxiety and Depression**

In the United States, selective serotonin reuptake inhibitors (SSRIs) are the most widely used antidepressants in children and adolescents. Fluoxetine is the only SSRI that has been FDA approved for the treatment of depression in children (Phipps et al., 2012). Very little information has been published regarding the use of antidepressant medications (specifically SSRIs) for treating depression in the pediatric oncology population (Kersun & Kazak, 2006). Some of the lack of data may be attributed to the FDA “black box warning.” In October 2003, the US Food and Drug Administration (FDA) issued a public health warning about the risk of suicide in pediatric patients taking SSRIs for depression. This black box warning has elicited a fear of prescribing antidepressants for AYAs. Among pediatric patients diagnosed with depression, the proportion who did not receive prescriptions for SSRIs increased to 3 times the rate predicted by the preadvisory trend (Libby et al., 2007). Additionally, rates of pediatric
patients with documented depression decreased substantially, suggesting a reduction in the actual diagnosis.

A 2012 study of 151 oncologists by Phipps et al. sought to understand practices of prescribing medication for depression and anxiety. Overall, oncology providers reported difficulties differentiating symptoms of depression from side effects of cancer treatment. The survey showed that mental health practitioners are not routinely consulted, and oncologists also reported a lack of mental health resources. Approximately half of oncologists reported that the FDA black box warning had affected their practice. In addition, only 28% reported monitoring patients on SSRIs at FDA-recommended intervals, and only 9% indicated assessing for suicidality. In a 2006 study, the recorded percentage of pediatric oncology patients who were prescribed antidepressants was approximately 10.2% (Portteus et al., 2006).

Pao, Ballard, Rosentstein, Wiener, and Wayne (2006) reported that the prescription rate for psychotropic drugs in the pediatric population had reached an estimated 6%, with stimulant and antidepressant agents most commonly prescribed. However, no cross-sectional study has ever looked at the use of psychotropic medications in AYAs with cancer. Despite the absence of definitive clinical data, antidepressants may be useful in treating symptoms of depressed mood in patients with cancer, such as pain, gastrointestinal tract distress, wasting, fatigue, anxiety, and cognitive impairment (Pao et al., 2006). Many medications used to treat anxiety and depression may have additional benefits in addressing physical symptoms associated with cancer and side effects related to its treatment. For example, benzodiazepines are frequently used to treat both anxiety and nausea due to chemotherapy. Stimulant medications may be used to treat fatigue and lethargy in adolescent cancer patients (Abrams et al., 2007).

Alternative therapies are available to treat psychological distress, such as cognitive behavioral therapy, guided imagery, massage, acupuncture, and music and art therapy. These modalities may have enormous potential for improving psychological outcomes, but few studies have examined their efficacy. Additionally, these therapies are not readily available in most hospital settings and usually are not covered by insurance (Abrams et al., 2007). In a recent study, AYAs ages 20 to 29 years were less likely than all others to report the use of traditional mental health counseling (Zebrack et al., 2013). Clearly, there is a need for readily available complementary and creative psychosocial interventions.

**Clinical Implications**

The discussion presented here has significant implications for pediatric nurses and nurse practitioners who care for AYAs with cancer. Pediatric clinicians will see this age group at an increasing rate since these patients generally have much better outcomes when treated in a pediatric center. Nurses have the advantage of spending more time with their patients and have a unique perspective on their holistic care. The patient-nurse relationship is built on trust, and AYA patients may share feelings and struggles that they would not tell their parents or physicians. Adolescents may try to avoid burdening their parents with their concerns. Therefore, it is important that AYAs have regular opportunities to talk to their providers without their parents being present, which is not currently routine. The staff may then acquire an increased understanding of adolescents’ concerns, and lack of concerns, which may help them to provide adequate information and support as well as prioritize care and resources (Hedstrom et al., 2006). Nursing is instrumental in developing the plan of care and can help ensure that care is tailored to the needs of the AYA patient and is not a one-size-fits-all approach.

Nursing can play a huge role in education for both patients and staff. Setting AYA patients up with proper resources and educating them about their illness may alleviate stress and anxiety. Oncology nurses and nurse practitioners have in-depth knowledge about side effects of medications and treatments and may have great ideas when it comes to their management. Advocating for AYA patients and keeping their best interests in mind when developing treatment plans is imperative. Nurses and nurse practitioners can help these patients achieve the goal of living as normal a life as possible by encouraging them to attend school when possible or join online support groups.

**Recommendations for Future Practice**

Increased training in communication and assessment skills may help staff to identify signs of distress and further distinguish between anxiety and depression. Furthermore, a psychosocial routine that is executed for every patient may be helpful. Such a practice would include AYA self-reports on psychosocial issues, a routine assessment or interview by physicians or nurses, and psychological assessments using a screening tool. Increased screening for depression and anxiety and the use of different screening tools would be helpful in identifying different types of distress. There is currently no validated tool to screen for anxiety and depression in this specific population.

Increased mental health resources are needed in both inpatient and outpatient settings. Mental health professionals should be included in the multidisciplinary treatment team, especially early in treatment. This may allow
for earlier detection of mental health issues and allow the patient and clinician to build the rapport and trust needed to address problems. There is also a need for mental health professionals who specialize in this population.

More research is needed on the utility of psychotropic medications in this population and on the efficacy, safety, and pharmacokinetics of these medications in AYAs. Additionally, alternative therapies should be explored and, if validated, made readily available. One such modality is cognitive behavioral therapy, which has been shown to decrease anxiety and depression and is associated with fewer relapses over time (Kurtz & Abrams, 2011). When providers do prescribe medications, monitoring practices should be consistent with the recommendations made by the FDA. This includes assessing for suicidality at regular intervals and educating both patients and parents about possible side effects.

To improve outcomes for AYA cancer patients, it is essential that services be developed within youth-friendly models. This requires awareness by the health care team that this population is unique in many ways: biologically, developmentally, psychologically, socially, and culturally. AYA care should be provided by professionals who understand the needs of this age group, in an age-appropriate environment. An ideal example of this is the Teenage Cancer Trust (TCT), which was established in the United Kingdom to ensure that AYAs with cancer have special provisions for their care (Morgan et al., 2010). In addition to providing support forums and resources for AYAs, the TCT funded the establishment of hospital units exclusively for AYA oncology patients. The units allow for camaraderie and support among patients and often have late wake-up and flexible visiting hours to promote a more relaxed environment. Patients in these units have reported much higher satisfaction and felt it was easier to adapt to their treatment. There is currently a trend in the United States of building AYA-specific cancer units to promote camaraderie and tailor the cancer experience to this population. The Alicia Rose Victorious Foundation raises money to build AYA lounges on pediatric oncology floors and distributes “teen kits” to AYA patients. Also needed are more interventions to promote social integration and school reentry for AYAs, for whom friendships and social roles are key components of identity and mental health.

Conclusions

Adolescents and young adults with cancer are a distinct subgroup of patients within pediatric oncology. Adolescence and young adulthood are periods of tremendous change, and a diagnosis of cancer can be incredibly distressing, thus contributing to the development of anxiety and depression. Due to the methodological limitations in most studies, it remains impossible to accurately determine the true prevalence of mood disorders in pediatric cancer patients receiving treatment. Early identification and intervention of depression and anxiety are imperative to avoid long-term emotional consequences and provide excellent oncologic care. Further research is needed for both pharmacologic and nonpharmacologic interventions as well as improved training for clinicians on how to recognize psychological distress. Finally, AYAs with cancer should not be strictly grouped into pediatric or adult arenas but, ideally, should be treated as a distinct population and offered customized mental health care.

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