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Anxiety among adolescent survivors of pediatric cancer: A missing link in survivorship literature

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Abstract

Objective—With growing numbers of pediatric cancer survivors, it is becoming increasingly important to investigate the psychosocial sequelae of surviving cancer diagnosed during childhood or adolescence. It is particularly important to study the psychosocial needs of adolescent survivors of pediatric cancer because adolescence is a critical time during psychosocial development. Although there is existent literature about the general psychosocial adjustment of this population, the literature regarding anxiety is scant. This brief review aimed to assess currently available literature that addresses anxiety in adolescent cancer survivors.

Method—Articles assessing psychosocial adjustment in adolescent survivors of pediatric cancer were reviewed for information regarding anxiety symptoms.

Results—To the authors' knowledge, there is no literature that focuses specifically on anxiety in this population. However, many of the articles reported results that indicated the possibility of increased anxiety in this group.

Significance of Results—It is critical to further investigate anxiety in this group and to develop appropriate interventions if necessary. Doing so will aid the process of enhancing psychosocial care for adolescent cancer survivors.

Keywords

adolescents; cancer; anxiety; survivorship

Introduction

Anxiety in Adolescents with Cancer

Being treated for cancer is a major source of stress at any age and, perhaps, particularly for children and adolescents. Children and adolescents with cancer are confronted with the

stress of understanding their disease and facing the possibility of dying at a young age. Furthermore, these patients undergo extended treatment plans that are often invasive, painful, and cause significant physical side-effects. These treatments are typically very disruptive to patients' lives, leaving children and adolescents with cancer to adjust to shifts in routine and changing relationships with family and peers (Decker, 2007).

Children and adolescents with cancer are potentially vulnerable to developing psychosocial difficulties due to the many challenges of cancer and its treatment. To date, anxiety is understudied in this population, despite convincing evidence that anxiety may be a common sequela of pediatric cancer. Kazak and colleagues' research (2004a; 2004b; 2005; 2006) on post-traumatic stress disorder (PTSD) and post-traumatic stress symptoms has forged the path for research in anxiety among adolescent survivors of pediatric cancer. However, the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V; American Psychiatric Association, 2013) recognizes PTSD as unique from other anxiety disorders by including it in a new diagnostic category. This change paves the way for new research involving currently defined anxiety disorders among adolescent survivors of pediatric cancer.

Anxiety has been found to be highly prevalent among cancer patients (Stark & House, 2000; Stark et al., 2002), indicating that the stress of the cancer experience can lead to the development of anxiety symptoms. However, specific research is needed to assess the prevalence and possible manifestations of anxiety in adolescents who have been treated for cancer. Adolescents are in a unique psychosocial phase that is crucial to identity development (Erikson, 1959; Steinberg & Morris, 2001), yet they tend to be grouped into studies with younger children or with adults. Adolescents with cancer should be considered as a unique group because they tend to experience distress that is more complex, severe, and long-lasting than children or adults with similar diagnoses, and this distress tends to be most prominent after ending active treatment (Sansom-Daly et al., 2012). However, little is known about the unique characteristics and needs of this population as related to anxiety.

Anxiety During Survivorship

Although achieving remission is certainly a welcome relief for pediatric cancer patients and their families, the transition into survivorship undoubtedly brings its own set of challenges, such as readjustment to home and family life, re-acclimation to school and social settings, uncertainty about cancer recurrence, and coping with residual physical effects of treatment. Research to date has typically found adolescent cancer survivors to be psychologically resilient (Phipps, 2007; Kazak et al., 2010; Williams, Allen, & Phipps, 2011); however, there is likely a subset of individuals who experience psychosocial difficulties following their transition into survivorship.

In fact, the period following cancer treatment may leave adolescents particularly vulnerable to developing anxiety and other psychosocial difficulties. A study by von Essen and colleagues (2000) found that survivors of pediatric cancer reported higher levels of anxiety and depression and lower levels of self-esteem than both healthy peers and children currently undergoing cancer treatment. Although these results became statistically insignificant after further analysis, the study's power may have been limited by a small

sample size ($n = 18$). Therefore, further research with a larger sample size is necessary to determine if adolescent cancer survivors' rates of psychopathology are truly higher than those of adolescents undergoing cancer treatment and healthy peers. If these findings were replicated, it would indicate that transition into survivorship may be a crucial time to intervene with adolescents who are experiencing psychosocial difficulties, including anxiety.

There has been a fair amount of research about the psychosocial functioning of adolescent cancer survivors. However, to the authors' knowledge, there have been no studies specifically assessing anxiety in this population. This gap in the literature is alarming, as there is meta-analytic evidence that anxiety may be more likely to present as a problem for cancer survivors than depression (Mitchell, Ferguson, Gill, Paul, & Symonds, 2013).

This paper will review relevant literature regarding psychosocial functioning among adolescent survivors of pediatric cancer with the aim of describing current knowledge about anxiety in this population and calling attention to gaps in the literature. An overview of current knowledge about anxiety in adolescent survivors of pediatric cancer is a starting point for the development of anxiety screening and prophylactic treatments for this population, which could prove to be useful in supporting psychosocial adjustment, not only during adolescence, but as these patients transition into adulthood.

Specific Phobias

Children and adolescents with cancer typically undergo many painful medical procedures, leaving patients and survivors vulnerable to procedure-related anxiety. In a study of pain management in children ages 3–18 undergoing medical procedures, Weisman, Bernstein, and Schechter (1998) found that children younger than 8 years old who had received the placebo on the first trial continued to feel high levels of pain during subsequent procedures performed with pain management. This pain is likely anxiety-related because young children lack the cognitive development to understand that subsequent procedures might not be as painful with proper analgesic medication. Longitudinal research is needed to determine if this effect continues to impact children as they enter adolescence. Additionally, some procedures may be painful enough to cause anxiety even with adequate analgesic. Such distress can lead to anticipatory anxiety, as well as specific phobias of blood, needles, etc., that could make future medical procedures difficult to withstand (Pao & Bosk, 2011). Specific phobias relating to medical procedures or medical settings would likely be detrimental to cancer survivors' health, as routine follow-up is necessary for optimal survivorship care.

Social Phobia

After spending a large portion of time in hospitals, doctors' offices, and at home, adolescents may face anxiety in unfamiliar social situations after completing cancer treatment. A large study conducted by Barrera and colleagues (2005) found that adolescent cancer survivors were more likely than healthy peers to have no close friends and less likely than healthy peers to use friends as confidantes. Similarly, Shelby and colleagues (1998) found that survivors of Acute Lymphoblastic Leukemia had more difficulty with social competence

than healthy peers, as well as more anxiety, depression, and overall internalizing symptoms. Taken together, these findings suggest a high prevalence of social difficulties among adolescent survivors of pediatric cancer. Further research is required to understand the role of internalizing symptoms (including anxiety and, perhaps, social anxiety in particular) as either cause or effect of social difficulties in pediatric cancer survivors.

Generalized Anxiety Disorder (GAD) and Panic Disorder (PD)

To the authors' knowledge, no studies have assessed the presence of discrete anxiety disorders such as Generalized Anxiety Disorder (GAD) and Panic Disorder (PD) in this population. However, there are studies that indicate the existence of various, unspecified anxiety symptoms. These studies point to the presence of increased anxiety in adolescent survivors of pediatric cancer, without specifically assessing for anxiety disorders.

In a large study of pediatric cancer survivors aged 5.8 to 36 years Koocher and colleagues (1980) found that the majority of participants experienced residual psychosocial sequelae, especially depression, anxiety, and low self-esteem. Participants who were able to articulate sources of their anxiety mentioned uncertainty about the future, the possibility of recurrence, and troubling memories of stressful aspects of treatment. Interestingly, death anxiety scores for participants were lower than those for a comparable control group of medically healthy peers, which may imply that the disease itself is more difficult to manage than the possibility of death. This study also found that post-treatment psychosocial difficulties became less prevalent as patients got further from the time of diagnosis if they remained relapse-free. Given the broad age range for participants in this study, it is necessary to conduct further, more age-specific research with adolescents in order to determine which of these findings, if any, may be particularly salient for this age group.

A study conducted by Bauld, Anderson, and Arnold (1998) compared the psychosocial functioning and coping mechanisms of Australian adolescents previously diagnosed with cancer with that of healthy adolescents recruited from the general population. Bauld and colleagues' findings generally pointed toward normal psychosocial functioning among adolescent cancer survivors. However this group demonstrated significantly higher state anxiety than healthy peers, and scored higher on two negative coping mechanisms, wishful thinking and ignoring the problem. Similar to the findings of Koocher and colleagues (1980), time elapsed since treatment was found to be a significant predictor of psychosocial adjustment, with longer times out of treatment being associated with better psychosocial functioning.

Despite the adolescent survivors' high levels of state anxiety, Bauld and colleagues (1998) generally found results that imply psychosocial functioning comparable to that of healthy peers. However, there are two factors to consider when interpreting these results. First, survivors' tendency to avoid problems supports the possibility of increased anxiety, as avoidant behavior is a key feature of anxiety. Therefore, it is possible that adolescent cancer survivors experience heightened levels of anxiety, but do not acknowledge these feelings due to their avoidance of anxiety-producing situations. Second, about 59% of the cancer survivors in this study had been out of treatment for more than 5 years. Therefore, results

can only be used as a measure of long-term coping. Further investigation is necessary to determine if these results are representative of adolescents in all stages of cancer survival. The results of von Essen and colleagues (2000) suggest that it is unlikely that survivors of all stages will fit a psychosocial profile similar to that of healthy peers. Additionally, Bauld and colleagues' results imply that even though survivors appear to have good long-term adjustment, it is possible that pervasive anxiety is camouflaged by maladaptive coping mechanisms, such as ignoring the problem or engaging in wishful thinking.

One recent study examined anxiety symptoms in adolescents with differentiated thyroid cancer (DTC). This study found that adolescents with DTC do not experience greater anxiety than adolescents with autoimmune hypothyroidism or healthy peers (Oren, Benoit, Murphy, Schulte, & Hamilton, 2012). However, these results may have been limited by a small sample size ($n = 16$). Furthermore, these findings cannot be generalized to adolescents with other types of cancer.

Comorbid Anxiety and Depression

In addition to the evidence supporting the presence of miscellaneous anxiety symptoms among adolescent survivors of pediatric cancer, it is important to note that Major Depressive Disorder (MDD) is prevalent among cancer patients and survivors (Massie, 2004). GAD and MDD are often found comorbidly, both in the general population (Aina & Susman, 2006) and in cancer patients (Cassileth, Lusk, Hutter, Strouse, & Brown, 1984). Therefore, it is important to investigate the prevalence of GAD and other common anxiety disorders, such as PD, among adolescent survivors. Future studies with adolescent survivors should address this gap in the literature.

Implications for Research and Practice

Overall, research points to normal psychosocial adjustment in adolescent survivors of pediatric cancer. However, there is evidence to indicate a possible vulnerability for anxiety among a subset of this population, particularly during the transition to survivorship. Studies to date have not typically differentiated between different types of anxiety; however, it seems that this population may be at risk for many forms of anxiety at both clinical and sub-clinical levels. However, there are currently no studies assessing for specific anxiety disorders or the presence of subsyndromal anxiety symptoms in this population, which indicates a large gap in the literature on psychosocial care for adolescent survivors of pediatric cancer.

It is possible that the stress of cancer diagnosis, treatment, and transition into survivorship may cause adolescents to experience a variety of anxiety symptoms. For instance, adolescent survivors of pediatric cancer may experience generalized anxiety, including health-related anxiety, or panic attacks. Adolescents who were forced to rely on their parents to a greater extent than same-age peers might experience a sense of separation anxiety when they finally have the opportunity for greater autonomy. Likewise, adolescents may experience social anxiety in relation to the social deficits found by Barrera and colleagues (2005) and Shelby and colleagues (1998). These examples are only a few of the ways that anxiety could potentially manifest in adolescent survivors of pediatric cancer.

The recent publication of the DSM-V has created an environment that lends itself to the assessment of psychopathology in populations that have not been thoroughly assessed to date. Examining how adolescent survivors of pediatric cancer fit in to the most current standards for anxiety disorders and exploring how anxiety might manifest uniquely in this population are important steps in understanding the psychosocial needs of this potentially vulnerable group of adolescents.

While coping and psychosocial adjustment seem to improve with time, it is important to note that even long-time survivors have been found to employ negative coping mechanisms more frequently than healthy peers. Perhaps early intervention regarding anxiety and other psychosocial difficulties experienced as patients end active treatment can ease the path of adjustment for survivors of pediatric cancer and decrease the likelihood of experiencing residual psychosocial sequelae. Further research is necessary to determine whether the anxiety experienced by adolescent survivors of pediatric cancer tends to be prominent enough to lead to the diagnosis of an anxiety disorder, to assess which anxiety disorders may be prevalent in this population, to explore subsyndromal anxiety symptoms and patterns of anxiety that are unique to them, to identify their common sources of anxiety, and to assess how anxiety in adolescent cancer survivors affects the trajectory of their psychosocial development. This information can be used to develop more effective interventions to detect and treat anxiety symptoms at an early stage in order to promote psychosocial well-being throughout all stages of survival and psychosocial development.

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