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The psychosocial effects of pediatric cancer on young adult cancer survivors

Jacob D. Schaefer
University of Northern Iowa

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Abstract

Childhood cancer is a current problem in our society. Today survivor rates are increasing. There are increased numbers of childhood survivors dealing with the after affects of cancer as they move into adulthood. Research correlations between childhood problems and adulthood problems have emerged. Issues of psychological, social, and physical concerns have created difficulties for childhood cancer survivors. However, there have been mixed results as some researches show healthy adaptation while others indicate abnormal daily functioning of children and young adults. Future research areas should focus on individual coping methods, social function of young adult survivors, and the human developmental process of childhood cancer survivors.

The Psychosocial Effects of Pediatric Cancer on Young Adult Cancer Survivors

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Abstract

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Michael D. Waggoner

Department Head of Educational Leadership,
Counseling, and Post Secondary Education

Abstract

Childhood cancer is a current problem in our society. Today survivor rates are increasing. There are increased numbers of childhood survivors dealing with the after affects of cancer as they move into adulthood. Research correlations between childhood problems and adulthood problems have emerged. Issues of psychological, social, and physical concerns have created difficulties for childhood cancer survivors. However, there have been mixed results as some researches show healthy adaptation while others indicate abnormal daily functioning of children and young adults. Future research areas should focus on individual coping methods, social function of young adult survivors, and the human developmental process of childhood cancer survivors.

The Psychosocial Effects of Pediatric Cancer on Young Adult Survivors

Pediatric cancer is prevalent in our society. Nine thousand five hundred pediatric cancer cases are estimated for 2006 (National Cancer Institute, 2006). Over the last several years' survival rates for pediatric cancer have improved. Between 1950-1954 pediatric cancer survival rates were at 20%, this increased to 80% between 1996 and 2003 (National Cancer Institute, 2006). This increase in the long-term survival of pediatric cancer has led to further research in the physical, emotional, and social effects of treatment for cancer on survivors.

There has been vast research completed on the pediatric cancer population. This research focused during childhood while patients were receiving cancer treatments. Research focused on understanding the psychological and social effects of cancer treatments on the young patients. An example of the pediatric research being completed is a journal article by Bessel (2001) researching the psychological, social adjustments, and quality of life of the cancer patients.

Recently, there has been a surge of research completed to understand the lingering effects cancer may have on the transition of former child patients into adulthood. Many articles have been completed such as the Humpl, Fritsche, Bartels, and Gutjahr (2001) article looking at the lives of the young adult survivors more than twenty years after treatment. The extent of existing research indicates cancer is not something that affects these young patients only during their time of treatment, but over the life process.

Childhood Studies

Psychological Impact of Medical Procedures

Researchers studying pediatric cancer patients found a variety of impact on physical, psychological, and social issues. The risk factors included: worries about death, poor self-esteem, decreased social ability, depression, and fears about attending school (Bessel, 2001). The findings from the study indicate cancer had a large affect on the individual patient.

Children often describe the types of feelings or memories they have related to cancer treatments. McGrath, Paton, and Huff (2004) in a qualitative study had a child with cancer discuss the effect of having chemotherapy “the chemo – because it made me very sick. It made me vomit a lot. “They just didn’t let me eat for awhile.” (p. 363). This quote describes the impact treatments can have on a child’s daily life. Another child describes a difficult social situation “Once your hair falls out, you can never go back. You become a person who sees life as unpredictable, so you should never waste it.” (Bessel, 2001, p. 352).

One area of treatment children are impacted by is the medical procedures preformed. Lumbar punctures are a routine procedure preformed to administer chemotherapy through the spinal column. A study by Chen, Zeltzer, Craske, and Katza (2000) looked into the memories cancer patients have from the lumbar puncture procedures. There were several findings from this study. Sixty-eight percent of patients were able to accurately remember the details of the lumbar puncture up to one week after the procedure. The researchers also found the procedures had a significant emotional impact on the children. Which elicited emotions such as fear and anxiety.

Research identified the cancer experience as a significant influence on a child. The events that take place during cancer treatments may impact the child's emotions, social function, and overall development. These affects can cause severe psychological problems and atypical adjustment issues.

Emotional Defenses

A particular focus of research in the pediatric cancer population has been the incidence of Post Traumatic Stress Disorder (PTSD). PTSD is common in a person who experiences trauma. PTSD has been a common finding in much of the research done with pediatric cancer population (Madan-Swain et al., 2000). The traumatic and invasive procedures performed during cancer treatment can leave a strong experience that last past diagnosis.

Madan-Swain et al. (2000) found PTSD symptoms in patients in their study looking at cancer and family functioning. The researchers found many of the participants in the study attempted to suppress or avoid the emotional reaction to the perceived trauma. Both psychological and physical effects of PTSD have been found in the pediatric population including: increased heart rate and arousal when near a hospital setting, intrusive thoughts, and nausea (Kazak, et al., 2004). The severe symptoms and diagnosis of PTSD suggest a large psychological impact on a child who receives cancer treatments.

Repressive Adaptation

Another area of research focused on children coping with cancer through the use of repressive adaptation. Some studies have found children to have a healthy adaptation to experiencing cancer. Other researchers have looked into a repressive adaptive style

where patients avoid or attempt to ignore the problems brought on by cancer (Phipps, Steele, Hall, & Leigh, 2001). Some of the symptoms found were similar to post traumatic stress symptoms (PTSS).

The study found higher incidents of repressive adaptation among the cancer population as compared to a general population (Phipps, Steele, Hall, & Leigh, 2001). It was common for patients who adopted this coping style to use it early and then maintain this method of coping throughout their treatment. The research methods used self-report measures, which may have been skewed due to underreporting of symptoms. This may be due to children avoiding the problems attributed to their cancer experience.

Social Effects of the Cancer Experience

Many children with cancer experience social difficulties. He or she may have problems with achieving typical developmental tasks such as making friends leaving them developmentally behind their peers. Incidents of social abnormalities include behavior difficulties and social insufficiencies (Mulhern, Wasserman, Friedman, & Fairclough, 1989). Vance and Eiser (2002) reported that both teachers and parents rate children with cancer lower in social competencies and leadership skills. Bone marrow transplant patients were found to have fewer friendships than the control group (Vance & Eiser, 2002).

Some of the children may have problems feeling different from their peers due to the experiences associated with cancer. "There are heaps of children in here. We just talk about having treatment. You can talk to them about your favorite stuff." (McGrath, Patton, & Huff, 2004 p. 363). This quote by a patient indicated the feelings of support they felt when discussing cancer with patients going through similar experiences.

Once a child return home this support may be limited. Many of the children express feelings of wanting to be normal or fit in with other children (Bessel, 2001). Social expectations of children can be demanding. These expectations are often complicated by the vast emotional and psychological problems of a child with cancer.

Educational Issues

Obtaining a normal education for a child treated for cancer can be difficult. There may be problems from long hospitalizations and side effects of treatments, which may cause learning disabilities. Bessel (2001) found 35% of the participants in one study had average grades and 20% had poor grades and needed to repeat a grade level. Cognitive disabilities were found when a patient received cranial radiation, which created difficulty in completing subjects such as math (Mulhern, Wasserman, Friedman, & Fairclough, 2001).

The researchers found some students missed up to 42% of the school year due to illness related absences. The combination of learning disabilities and school absences can make it difficult for a child to get a proper education. Education is essential for success in most cultures. The school related problems could have lasting effects throughout the child's life and affect both academic functioning and self-esteem.

Child Development

Children who experience cancer have an atypical life event that takes place through a typical developmental process. Hauser et al.(as cited in Madan-Swain et al., 2000) found an illness such as cancer may have an unhealthy developmental influence in personal identity. Thompson and Hooper (as cited in Madan-Swain et al., 2000).

concluded patients suffering from PTSD may have increased difficulty in forming a healthy identity.

Several areas of life influence human development. Children being treated for cancer are less likely to explore alternative views of life and may be more easily influenced by those around them (Madan-Swain et al., 2000). Children generally adopt the belief system or identity of the adults around them such as doctors, parents, and peers. The child is less likely to explore his or her own ideas about life and self-identity. This could have consequences in the future as one's identity becomes increasingly important in later stages of development.

Adulthood Studies

General Impact of Childhood Cancer on Adult Survivors

Although most pediatric cancer survivors complete medical treatment, the lingering effects of cancer can affect individuals into adulthood. Young adult pediatric cancer survivors face new challenges as they experience the next stage of life and work to achieve normal developmental tasks. Issues such as forming relationships, infertility, cognitive defects, and emerging health related problems create difficulties for former patients (Hobbie et al., 2000). These issues could create problems for adult survivors both physically and psychologically.

A pediatric cancer survivor's understanding of his or her disease changes over time. This change can still occur even if the individual has been off treatment for a lengthened period of time. When a survivor enters adolescence he or she has an increased awareness of being a cancer survivor (Kazak, Christakis, Alderfer, & Coiro, 1994). The survivor

begins to understand how he or she differs from his or her peers including, appearance, past experiences, and personal abilities.

If these problems are not addressed, they can follow the survivor into adulthood. These new realizations may affect individuals differently. However, research makes clear that being treated for cancer has a lasting impact on each individual (Patenaude & Kupst, 2005). It is important to understand the different issues young adult survivors face to help them transition into adulthood.

Post Traumatic Stress Disorder

PTSD has been an issue that has followed cancer survivors from childhood into adulthood. Schwartz and Drotar (2005) found cancer survivors were five times more likely to suffer PTSD than the research control group. The researchers found this population demonstrated poorer quality in both physical and psychological aspects of daily life. Some survivors demonstrated avoidant or physical arousal symptoms when issues related to health were discussed (Hobbie et al. 2000). Hobbie et al. (2000) also found both physical and psychological responses in former childhood cancer patients ten years post treatment.

The evidence of PTSD on children during treatment and adults post treatment indicates pediatric cancer effects individuals throughout their lifetime. PTSD is one of the more extreme issues in this population. There are many factors young adult pediatric cancer survivors are facing as the move into adulthood.

Reoccurrence

One of the biggest problems facing pediatric cancer survivors is the fear of cancer reoccurrence. Prouty, Ward-Smith, and Hutto (2006) found participants in their study had

significant fears related to life longevity, fear of cancer reoccurrence, and having health consequences from late effects of previous cancer treatments. In a study by Meadows, McKee, and Kazak (1989) almost half of the sample reported worries about getting another cancer although they had one or fewer types of illness with in the last year of the study. Zebrack and Chesler (2001) found almost half of their sample indicated worry about getting another cancer or passing cancer onto their children. These studies show cancer is a continuous concern for pediatric cancer survivors.

Social and Vocational Issues

Maintaining a healthy and normal social life can be difficult for childhood cancer survivors. Having cancer at an early age can create differences from their peers. At times these differences can affect how peers relate to them and could possibly create stigmatization. These experiences often stay with survivors into adulthood. They continue to affect social relationships (Zebrack & Chesler, 2001).

Much of the problems begin to materialize in adolescence. Many adolescent survivors indicated the importance of peer relationships and worry about stigmatization (Zebrack & Walsh-Burke, 2004). A study by Zebrack and Chesler (2001) found participants commenting on feeling different from their peer group. Duffey-Lind et al. (2006) found similar results with members of the study reporting survivors had difficulty with feelings of isolation and reestablishing peer relationships while transitioning off of cancer treatments.

Many of these problems have continued into the young adult population. Some adult survivors of pediatric cancer identify losing a normal childhood and feeling like they do not blend in with their peer groups (Parry & Chesler, 2005). As a result many attempt

to compensate by working to be as normal as possible. Some survivors avoided sharing their cancer history with coworkers and peers (Prouty, Ward-Smith, & Hutto, 2006). Some members of the study went to great lengths to hide their cancer history. Social relationships become increasingly important as people age. As a survivor grows this takes a new turn with dating relationships.

Dating and marital relationships are a major part of the developmental process. This process may be difficult for young adult pediatric cancer survivors who have to make decisions about revealing their cancer background to their potential partners (Zebrack & Walsh-Burke, 2004). A study by Meadows, McKee, and Kazak (1989) reported 21% of the participants indicated cancer caused difficulty in meeting others, and 38% stated cancer scared off potential partners. Young adult survivors who marry have also been found to be lower in the young adult survivor population than the general population (Rauck, Green, Yasui, Mertens, & Robinson, 1999).

Previously the author included childhood patients were at risk for educational problems. This can create issues later in life related to careers and vocations. Duffy-Lind et al. (2006) reported one of the biggest fears children had transitioning off treatment was going back to school. Social workers in the adolescent and young adult cancer population indicated major concerns for their patients falling behind in either school or college (Zebrack & Walsh-Burke, 2004). The participant sample in a study by Mulhern, Wasserman, Friedman, and Fairclough (1989) reported 30% were having academic problems. If these problems are not address early they can affect survivors working capacity. In a study of 167 participants between the ages of 18-35 only 52.6% were in full

time positions. Of the participants in full time jobs 51.6% of those were in professional roles.

It is a success that patients being diagnosed with cancer have increased survival rates. However, cancer continues to affect the patients long after treatments have ceased. Issues like fear of reoccurrence, not having peer relationships, inability to have romantic relationships, and difficulty with employment greatly decrease a survivor's quality of life. It is also difficult to pinpoint the extent of problems caused by treatments and in turn find solutions due to the contrast of conclusions in the research itself.

The current bulk of research has mixed findings in the investigation of effects pediatric cancer has on patients. Some researchers have found the experience does not seem to have a large impact in a child's function, and the study participant's rate is similar to the control populations (De Clercq, Fruyt, Koot, & Beniot, 2004). Others have noted problems involving emotional, physical, and social issues (Bessel, 2001). Some of the researchers have attempted to identify patients within the population differing in life function. Finally, much of the researchers have stated findings with mixed results (Duffey-Lind et al., 2006). Contrast in research conclusions may point to significant problems within the cancer population, but identifying severity of problems may be difficult.

Healthy Functioning Outcomes

Several study results suggest the childhood cancer survivor population showed no difference in significant distress such as depression in comparison to the general population (Makie, Hill, Kondryn, & McNally (2000). De Clercq, De Fruyt, Koot, and Benoit (2004) found the population in the study was comparable in function and some of

their participants indicated having had cancer as an overall positive experience. These findings imply, although having had cancer as a child may have an impact, it does not dictate poor overall functioning.

Unhealthy Functioning Outcomes

Other areas of research have found members of this population to have noteworthy distress. In several studies nearly half of the population had significant psychological or social issues (Bessel, 2000; Mulhern, Wasserman, Friedman, & Fairclough, 1989; Schwartz & Drotar, 2006). One of the psychological concerns was PTSD. Hobbie et al. (2000) showed 20.5% of the study population met DSM-IV criteria for PTSD. These findings contradict those showing healthy adjustment.

Although the findings contradict, there continues to be patterns of significant problems within the population. Mackie, Hill, Kondryn, and McNally (2000) reported pediatric cancer survivors showed inferior quality in working through areas of daily function. Many young adult cancer survivors' reported worries or problems even years after completing treatment (Zebrack & Chesler, 2001).

Significant Distress in Small Portion of Survivors

Individual survivors may react differently to cancer diagnosis and personal development as treatments are completed. Kazak, Christakis, Alderfer, and Cioro (1994) recognized although the majority of study participants rated within normal adjustment, a significant subgroup were found to have distress. Schwartz and Dotar (2005) had similar findings when the majority of survivors demonstrated typical adjustment, but a small portion had PTSD. Psychological adjustment of pediatric cancer might be a complex process for each individual. An accurate understanding of adjustment may be difficult to

obtain from traditional research methods. Some research findings have shown possible opinions in broader terms of adjustment (Schwartz & Dotar, 2005).

Cancer Impact

Due to a variety of findings understanding the full impact of the cancer experience on a child remains unclear. The experience of childhood cancer is considerable, and has both positive and negative outcomes (Prouty, Ward-Smith, & Hutto, 2006). Many children with cancer appear to cope with the physical and psychological effects. However, the coping of each individual child contrasts (Swayer, Streiner, Antoniou, Toogood, & Rice, 1998). Regardless of the outcomes it is clear a child who is treated for cancer is impacted from childhood and into adulthood.

Research Methodology

One possible explanation of the contrast in research findings is the methods in which studies are completed. Issues of children using a repressive adaptation coping style could lead to under reporting of problems on self-report surveys (Kazak, Christakis, Alderfer, & Coiro, 1994). Completed research has a wide variety of focus and subject samples. This can create problems when attempting to understand a complex problem like the long-term effects of childhood cancer. Patenaude and Kupst (2005) discussed issues such as participant ages, level of treatment, and comparison groups as several possible methodological flaws. Finding answers will continue to be difficult until researchers can agree on the appropriate research methods for studying this population.

External Factors

A child treated for cancer will also have a variety of experiences during his or her lifetime contributing to the way they function in the world. Zebrack and Chesler (2001)

commented on the meaning an individual survivor contributes to having cancer and their general life outlook and how this impacted his or her overall function. Factors like socioeconomic status, gender, physical consequences of cancer treatments, and number of relapses all have an effect on a particular individual (Mulhern, Wasserman, Friedman, & Fairclough, 1989). Due to a variety of circumstances the effects of cancer and needs of young adult survivors continues to be a needed area of research (Duffey-Lind et al., 2006).

Issues concerning cancer may take on new meaning as a child continues on their developmental process. There has been little research dedicated specifically to cancer impact on the human developmental process. It is plausible a child treated for cancer may have an atypical development compared with healthy individuals.

Pediatric Cancer Developmental Process

The typical developmental process is altered for the child who is diagnosed and treated for cancer. Childhood cancer patients deal with issues like mortality, physical, and emotional trauma (Parry & Chesler, 2005). The issues of death or mortality are focused on stages of late adulthood according to the developmental table (Papalia, Olds, & Feldman, 2007). Concepts such as self-identity are also formed during early childhood and adolescence (Papalia et al., 2007). Conflicts potentially exist between being identified as different and a desire to be normal (Prouty, Ward-Smith, & Hutto, 2006). Using a developmental model also may help explain later occurrences of PTSD in survivors as his or her understanding of death changes as the person ages (Hobbie et al., 2000; Papalia et al., 2007). The atypical developmental event of childhood cancer could

potentially contribute to a different developmental process for childhood cancer survivors.

Conclusion

Regardless of how an individual diagnosed with cancer functions as a young adult, the cancer experience leaves a lasting impression. Frequent themes have emerged through studies that transcend over time. Common issues such as educational deficits, social competencies, psychological trauma, and issues regarding mortality are present in research studies focused on children and young adult survivors.

The way an individual childhood cancer survivor copes with these issues varies. Some function within normal limits compared to the general population. Others develop serious psychological issues. Understanding why individuals vary on coping styles is difficult to determine due to a variety of external life events other than cancer.

It is important for future research to focus on the themes emerging in childhood and expanding throughout the survivor's development. Emotional, social, educational, and physical deficits may affect a survivor differently throughout time. In addition future research should also focus on understanding the human developmental process of childhood cancer survivors in contrast to normal childhood development.

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