

# The Research Connection

## The Psychosocial & Nursing Advisory Board to the New Jersey Commission on Cancer Research

Editor: Kathleen Neville, Ph.D., RN

Number 2

The Joint Psychosocial & Nursing Advisory Group to the NJCCR was appointed to advise the Commission of special research needs pertaining to nursing, psychology, sociology, and related disciplines for the purpose of addressing gaps in vital areas of cancer research and cancer care in New Jersey.

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### Introduction to Posttraumatic Stress Disorder

By

Kathleen Neville, Ph.D., R.N. Professor, Department of Nursing, Kean University

Historically, the term Posttraumatic Stress Disorder (PTSD) has its origin from wartime experiences, beginning with the Civil War and continuing through every war thereafter. PTSD is a well documented condition, but has been named differently with each war. After the Civil War, due to autonomic cardiac symptoms experienced by soldiers, the term Soldier's Heart or Irritable Heart was applied to symptoms similar to what is now referred to as PTSD. In World War I, the term used was Shell Shock, and it was believed to have occurred from brain trauma from exploding artillery. Among World War II veterans, survivors of Nazi concentration camps, and survivors of the atomic bombings in Japan, as well as survivors of the famous Coconut Grove nightclub fire in Boston, similar symptoms (characteristic of PTSD) were referred to as Combat Neurosis, Operational Fatigue, Stress Reaction. During the Vietnam War era, the term Posttraumatic Stress Disorder was first utilized and gained attention and visibility from both the health care and public community as a significant mental health problem affecting approximately thirty percent of Vietnam veterans (Kaplan & Sadock, 1998). In recent years, researchers have focused on descriptive investigations of PTSD among cancer survivors, as well as multivariate explorations of psychosocial factors associated with PTSD in oncology populations across all age groups.

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The fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (1994) describes PTSD as a set of typical symptoms that develop after a person witnesses, is involved in or hears of an extreme traumatic and overwhelming stressor. Reactions to this experience are fear, helplessness, persistent reliving of the experience, and attempts to avoid being reminded of it (Kaplan & Sadock, 1998). Diagnostic criteria include exposure to a traumatic event, and the symptoms of reexperiencing, avoidance, and hyperarousal which lasts more than one month; however PTSD may not present for months or even years after the stressful event (Kaplan & Sadock, 1998). Clinical features of PTSD consists of disturbing reexperiencing of the event, avoidance patterning, emotional numbing, and consistent hyperarousal.

Recent inquiry is and will continue to focus on PTSD as a sequelae of the cancer experience for individuals and families. While PTSD can occur in any group, young adults are believed to be highly vulnerable. Future research examining subjective responses to treatment, coping patterns, social support, and other psychosocial variables is vital to the expansion of knowledge regarding predisposing factors to the development of this disorder.

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# Posttraumatic Stress in Pediatric Oncology

by
Larissa Labay, Psy.D.
Pediatric Psychology
Cure and Beyond
A Childhood Cancer Survivorship Program
Tomorrows Children's Institute
The Joseph M. Sanzari Children's Hospital
Hackensack University Medical Center

As the number of children surviving childhood cancer increases, there has been a growing interest in long-term psychological sequelae associated with the cancer experience. A number of studies have found that although the majority of survivors and their family members adjust well following the cessation of cancer treatment, there is a subset of individuals who experience ongoing psychological distress during the survivorship years (Kazak, 1994). The anxiety and avoidance symptoms reported by these individuals are consistent with a trauma response, and have led some researchers to argue that a post traumatic stress framework may be the most appropriate way of understanding the nature of psychological distress

experienced by childhood cancer survivors and their families (Rourke et al., 1999). Such a perspective emphasizes the uncertain and life threatening nature of the illness, as well as the intrusive and often painful medical procedures, lengthy hospitalizations, and separations from family and friends that are common throughout cancer treatment.

The essential feature of Posttraumatic Stress Disorder is the development of symptoms of re-experiencing, avoidance, and arousal following exposure to a traumatic stressor, in this case, "learning that one/one's child has a life threatening illness" (Diagnostic and Statistical Manual of Mental Disorders-IV, 1994). The types of symptoms commonly reported by cancer survivors and their family members include intrusive thoughts of cancer, fear of recurrence, avoidance of cancer-related reminders (e.g., doctors, hospitals), nightmares, and increased arousal. Perhaps one of the greatest concerns among medical and psychosocial staff is the extent to which PTS symptoms interfere with survivors pursuing routine long-term medical follow-up.

Research examining PTSD in survivors of childhood cancer has found that 14.2% of child and adolescent survivors score in the moderate to severe range on measures of PTSD (Kazak et al, 1997). Increased rates of PTSD have also been found in family members. Specifically, 40.2% of mothers, 31.2% of fathers, and 29% of healthy siblings score in the moderate to severe range on measures of posttraumatic stress (Kazak et al., 1997; Alderfer et al., in press). For parents and siblings, these rates are higher than those found in comparison groups. While some survivors and family members meet full criteria for PTSD, there are even more who report sub-clinical levels of PTS symptoms associated with the cancer experience.

As the prevalence of PTSD is documented among survivors and their families, there has been an effort to identify variables that differentiate those who adjust well following cancer treatment and those who experience ongoing difficulties. Among the patient population, those children who were more anxious during treatment are more likely to develop symptoms of PTSD (Kazak et al., 1998). Other factors that were found to be predictive of posttraumatic stress symptoms include perceived life threat (past and current) and perceived treatment intensity (Hobbie et al., 2000). Interestingly, objective ratings of treatment intensity and medical late effects are not predictive of posttraumatic stress, emphasizing the importance of subjective perception of the cancer experience in the development of PTS symptoms (Hobbie et al., 2000). Finally, higher levels of perceived social support has been associated with fewer symptoms of posttraumatic stress among survivors and their families (Kazak et al, 1997).

The course of PTSD and PTS symptoms among survivors is variable and at times symptoms are not immediately apparent. For example, one study reported that 20.5% of young adult survivors met criteria for PTSD, which is significantly higher than levels noted in child and adolescent survivors (Hobbie et al., 2000). This

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developmental difference appears to be related to the multiple transitions experienced during young adulthood and the need to take a more active role in managing health, occupational, and educational concerns (Hobbie et al., 2000). As these issues become more prominent for the young adult survivor, the impact of the cancer experience and related late effects begin to take on new meaning.

Research findings suggest a number of possible areas for intervention to reduce symptoms of PTS in survivors and family members, and many pediatric oncology centers have started to implement such interventions. In some cases, the focus is on reducing the symptoms experienced by long term survivors through individual, group, and family therapy These interventions involve validating interventions. symptoms as common to survivors and family members, teaching and reinforcing coping strategies, providing information regarding late effects, and helping survivors to identify those risk factors that are controllable, such as diet, lifestyle, and preventative health care (Hobbie et al., 2000). Another approach is through primary prevention, which involves intervening during the active treatment phase to reduce the incidence of PTSD before it occurs. interventions involve reducing anxiety in children, providing developmentally appropriate knowledge regarding cancer, offering adequate preparation for medical procedures, reducing perceptions of life threat and treatment intensity, facilitating access to sources of social support, and providing strategies for more effective coping (Stuber et al., 1997). Taken together, findings of elevated rates of PTS symptoms and the documented effectiveness of psychosocial interventions in reducing these symptoms illustrate the importance of comprehensive health services that incorporate quality of life issues into the routine care provided to pediatric oncology patients and their families.

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# Clinical Interventions in the Treatment of Posttraumatic Stress Disorder

by Lissa Parsonnet, Ph.D., ACSW Private Practice Short Hills, New Jersey

While cancer as a traumatic event has never been disputed, the application of Posttraumatic Stress Disorder (PTSD) to the cancer population has evolved as the diagnostic criteria for PTSD has shifted from an emphasis on the traumatic event toward the psychological experience of the individual impacted by the event (Passit & Grummon, 1998). DSM-IV includes life-threatening illness in the list of actual or perceived threats that may provoke a diagnosis of PTSD, paving the way for researchers to expand examination of the prevalence of this diagnosis among cancer survivors. The prevalence of PTSD among cancer survivors is difficult to quantify, in part because cancer involves serial, rather than single-incidence trauma. Diagnosis, surgery, initiation of localized or systemic treatment, side-effects, termination of treatment, and recurrence can each be experienced as a traumatic event, so that symptoms of PTSD may develop at any point in the treatment continuum.

According to the Diagnostic and Statistical Manual of Mental Disorders IV(APA, 1994), PTSD is characterized by recurrent, intrusive, and distressing images, thoughts or perceptions of the traumatizing event; persistent avoidance of stimuli associated with the trauma, generalized numbing of emotional responses, and increased emotional arousal. In addition to the disabling impact these phenomena can have, without effective treatment patients may try to avoid symptoms through the use of maladaptive or dangerous behaviors including the use of alcohol or drugs. The very avoidance that characterizes PTSD often prevents or delays the effective treatment of this personally disabling condition (Passik & Grummon, 1998).

The National Center for Post-Traumatic Stress Disorder (NCPTSD) (2003) lists the following as common components of PTSD treatment:

- Education of trauma survivors and their families about what PTSD is, how it can impact survivors and those close to them, and that it occurs in "normal" individuals who are subjected to situations of extreme stress.
- Exposure to the event, often using imagery, in a safe, controlled environment.
- Examination and resolution of strong feelings associated with the event. Such feelings commonly include anger, shame, or guilt.
- Instruction in coping skills to manage posttraumatic memories, reminders, reactions and feelings.

In offering these components, a number of modalities are used to treat PTSD.

Cognitive-behavioral therapy (CBT) involves working with beliefs or cognitions to alter emotional responses and behaviors. At its foundation, cognitive therapy is based on the belief that affect and action are largely determined by the way in which an individual's beliefs about the world are structured (Beck, 1976). In the case of PTSD, CBT techniques may include desensitization, in which the patient and therapist create a hierarchy of traumatic memories and reminders. Each item on the hierarchy is confronted in imagery, and then paired with relaxation techniques, thus desensitizing the memory or trigger from the feelings of panic or anxiety. Other CBT techniques include learning specific skills, including relaxation training, cognitive restructuring, communication skills, and stress inoculation to help to manage the intense memories and feelings when they do arise (NCPTSD, 2003).

**Pharmacological Agents** are frequently used to augment and in some cases enable psychotherapy. Medications can be quite effective in managing the anxiety, depression, and insomnia that often accompany a PTSD diagnosis (NCPTSD, 2003).

**Eye Movement Desensitization and Reprocessing** (EMDR) began as a therapy designed to treat PTSD (Shapiro, 2001a). In the case of a cancer diagnosis, Shapiro (2001a) writes that "The assault on the psyche of the client may be just as severe - or even more severe - when the perpetrator is perceived to be the client's own body" (p.234). Through the use of a very specific protocol, using bilateral stimulation (eye movements, hand taps, or sound), EMDR

clinicians use a three-pronged approach to helping patients to reprocess trauma. The cognitive and affective structure of the original trauma is addressed; current triggers of symptomatology are identified; and more adaptive cognitive/behavioral responses are "installed" (Shapiro, 2001b).

**Group Treatment** is often an effective way to work with trauma survivors. Group interventions enable members to achieve enhanced understanding and resolution of their trauma. Relating ones experiences in this safe, cohesive and empathic setting can enable survivors to directly face the grief, anxiety, sadness etc. associated with the traumas, helping many survivors to cope with reminders of the trauma (NCPTSD, 2003).

**Brief psychodynamic psychotherapy** addresses conflicts aroused by the trauma, which may relate to early life experiences. The goal of this therapy with this population would be to identify current life situations, as well as earlier life experiences, that may be trigger traumatic memories, and exacerbate PTSD symptoms (NCPTSD, 2003).

The effects of PTSD on cancer survivors can be profound and lasting, impacting both the quality of on-going follow-up and care, as well as quality of life. Interventions are available to help reduce and manage symptoms. It is critical that these interventions are available to survivors.

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