Brief Report: Post-traumatic Stress During Emerging Adulthood in Survivors of Pediatric Cancer

Cynthia A. Gerhardt,1 PhD, Justin M. Yopp,1 PhD, Lindsay Leininger,1 BA, Kristin S. Valerius,2 MA, Judy Correll,3 RN, CPNP, Kathryn Vannatta,1 PhD, and Robert B. Noll,4 PhD

1Center for Biobehavioral Health, Columbus Children’s Research Institute and The Ohio State University, Columbus, OH, 2Section of Developmental and Behavioral Sciences, Children’s Mercy Hospital, 3Division of Hematology/Oncology, Cincinnati Children’s Hospital Medical Center, Cincinnati, OH, and 4Child Development Unit, Children’s Hospital of Pittsburgh, Pittsburgh, PA

Objective To examine post-traumatic stress symptoms (PTSS) and disorder (PTSD) among survivors of childhood cancer and comparison peers during the transition to emerging adulthood.

Method From elementary and middle school, we prospectively followed a cohort of 56 cancer survivors, 60 comparison peers, and their parents. Assessments were completed after the youth’s 18th birthday using questionnaires and a semi-structured psychiatric interview. Healthcare providers rated treatment severity and late effects.

Results Survivors and comparison peers did not differ on rates of PTSS or PTSD, but comparison peers reported more dissociative experiences than survivors. Late effects were associated with a greater number of past PTSS. Of the 16 cancer survivors who reported a traumatic event, five (31%) were cancer-related.

Conclusions Levels of PTSS were similar for survivors and comparison peers. Research with other potentially traumatic diseases or treatments (e.g., amputations, brain tumors) is needed. The role of methodology and contextual factors in the assessment of PTSS/PTSD is discussed.

Key words adjustment; adolescents, neoplasms; post-traumatic stress.

One in every 640 young adults is a survivor of childhood cancer (Lipschitz, Weiner, & Hewitt, 2005) highlighting the importance of examining long-term quality of life. Post-traumatic stress symptoms (PTSS) have received particular attention due to children’s repeated exposure to painful procedures, hospitalizations, and uncertain prognoses. Trauma models suggest that a cancer diagnosis and/or its treatment may serve as primary or secondary traumatic events, which may elicit PTSS such as re-experiencing, avoidance/dissociation, or hyperarousal (Stuber, Kazak, Meeske, & Barakat, 1998). Although survivors rarely meet criteria for Post-traumatic Stress Disorder (PTSD; e.g., Erickson & Steiner, 2001), individual symptoms or clusters of PTSS have been reported (e.g., Brown, Madan-Swain, & Lambert, 2003; Kazak et al., 2004) and may vary widely from 19% (Barakat et al., 1997) to 88% of survivors (Erickson & Steiner, 2001). This may depend on whether past or current symptoms were examined, as well as the format for queries. Considering the growing number of survivors and the potentially detrimental impact of PTSS, further exploration of this issue is important.

Survivors entering early adulthood may be especially vulnerable to PTSS compared to children or adolescents (Barakat et al., 1997; Hobbie et al., 2000). This may result from the typical challenges of early adulthood (e.g., forming intimate relationships, making independent financial and health care decisions) or changes in brain biology as the forebrain and other neurological structures that contribute to judgment and perspective taking mature.
In addition, medical late effects (e.g., organ toxicities, secondary malignancies) may become more evident in early adulthood and increase distress (Bhatia & Landier, 2005). Although objective ratings of treatment severity have not been associated consistently with PTSS (Taieb, Moro, Banhet, Revah-Levy, & Flament 2003), medical late effects may be more proximal and relevant for survivors as they enter adulthood. These late effects may exacerbate PTSS or serve as new traumatic events that threaten adjustment (Boman & Bodegard, 2004; Brown et al., 2003). Thus, understanding the adjustment of survivors and the role of medical late effects is important as survivors enter emerging adulthood and transition to adult healthcare providers.

This study compared the types of traumatic events and PTSS found among childhood cancer survivors and comparison peers. Comparison peers were selected based on their demographic similarity to survivors to examine the occurrence of PTSS due to having a history of cancer above and beyond the base rates for trauma and stress in a community sample without an illness. We expected that survivors would have higher rates of current and past PTSD, PTSS, and dissociative experiences than comparison peers and that the severity of medical late effects would increase risk for these problems.

**Method**

**Participants**

Participants were part of a longitudinal study of family adjustment to childhood cancer (Noll et al., 1999). At initial enrollment, participants were (a) 8–15 years of age, (b) on initial treatment for non-CNS cancer, (c) attending school and not in full-time special education, (d) English speaking, and (e) living within 50 miles of the hospital. Of the 103 participants who met inclusion criteria, 100 participated in initial data collection. Of these 100 children, 63 survivors were eligible for the second phase after turning 18 years old, and 56 (89%) participated. Thirty-nine percent (n = 22) had lymphoma, 37% (n = 21) leukemia, and 24% (n = 13) solid tumors. Average time since diagnosis was 7.29 years (SD = 2.17, range = 3.58–12.25). The sample was 66% (n = 37) male and 93% (n = 52) Caucasian, with a mean age of 18.63 years (SD = .75).

At initial data collection, each survivor was matched to a classmate for gender, race, and date of birth. These comparison peers and their parents were contacted for follow-up after peers reached their 18th birthday. Of the 100 original comparison peers, 77 were eligible, and 60 (78%) participated in the second phase. The comparison group was 63% (n = 38) male and 93% (n = 56) Caucasian, with a mean age of 18.62 years (SD = .71).

**Procedure**

Following approval by the institutional review board, families were invited to participate in the current follow-up soon after the child’s 18th birthday. Participants provided written informed consent, and trained research assistants collected data in the home to eliminate potential confounds related to emotional reactions to the medical center that might be different between groups. Families were compensated for their time.

**Measures**

**Demographic Questionnaire (Noll et al., 1995)**

Parent-report of background characteristics (e.g., education, marital status) was assessed. Socio-economic status (SES) was computed using the Revised Duncan (Nakao & Treas, 1992).

**Kiddie-Schedule for Affective Disorders and Schizophrenia-Epidemiologic Version-5 (K-SADS-E-5; Orvaschel, 1995)**

This semi-structured interview assesses symptoms of DSM-IV disorders in youth ages 6–18 years. A trained graduate student in clinical psychology interviewed parents and youth separately. If the two respondents disagreed on past (i.e., any lifetime symptoms) or current (i.e., at the time of interview) symptoms of PTSD, the discrepancy was discussed, and a consensus was reached based on standardized rules and clinical judgment. If a traumatic event was reported on the first two screening questions, 17 current and lifetime PTSS were assessed. Participants were not asked about PTSS if no traumatic event was reported. The K-SADS-E-5 has good reliability and validity (Ambrosini, 2000). Inter-rater reliability was κ = .87 for past and κ = .85 for current symptoms in this study. It has been used previously to assess psychopathology in emerging adults (e.g., Deas, St. Germaine, & Upadhyaya, 2006).

**Adolescent Dissociative Experiences Scale-II (A-DES; Armstrong, Putnam, Carlson, Libero, & Smith, 1997)**

This 30-item self-report measure assesses dissociative experiences in youth ages 10–21 and has been used...
frequently in trauma research. It is particularly useful due to its ability to assess symptoms of avoidance/dissociation and to distinguish among normal youth and those with a history of trauma or other psychiatric disorders (e.g., Deseth, 2006; Muris, Merckelbach, & Peeters, 2003). Survivors and comparison peers rated the frequency of dissociative experiences on a scale of 1 (never) to 10 (always). Higher total scores indicated more dissociative experiences. The A-DES had good reliability and validity (Armstrong et al., 1997; Farrington, Waller, Smerden, & Faupel, 2001; Seeley, Perosa, & Perosa, 2004). Internal consistency for this study was α = .94.

Treatment Severity
Two pediatric oncologists rated each survivor’s initial treatment protocol from least (1) to most (10) severe using a forced choice technique (Noll et al., 1999). Rankings correlated 0.82, suggesting consistency between raters. Average treatment severity was 5.62 (SD = 1.04) for this sample.

Medical Late Effects
Similar to previous work (Mulhern, Wasserman, Friedman, & Fairclough, 1989), the severity of late effects for survivors was coded at follow-up by a nurse practitioner from 0 to 3 (i.e., none, mild, moderate, and severe) in each of four categories (i.e., cosmetic impairments, functional impairments, learning problems, and other organ toxicities). This resulted in a total late effects score. The average score for this sample was 1.00 (SD = 1.04, range 0-4), with 59.2% (n = 29) having at least mild evidence of one late effect.

Results
Between-group Comparisons for Background Variables, PTSD, and PTSS
Families of survivors and comparison peers did not differ on a variety of background variables (e.g., SES, parental education, or age), and mothers of survivors were equally as likely to be married (78%) as mothers of comparison peers (83%). χ²(1, n = 114) = 0.56, p = n.s. Two survivors (3%) and four comparison peers (6%) met criteria for past or current PTSD. Contrary to expectations, only four survivors (7%) and five comparison peers (8%) reported currently having at least one PTSS, while 11 survivors (20%) and 8 comparison peers (13%) reported at least one PTSS in the past, χ²(1, n = 114) = 0.85, p = n.s. T-tests indicated a trend in an unexpected direction on the A-DES, t(114) = 1.95, p = .05, with survivors (M = 30.11, SD = 29.50) reporting fewer dissociative experiences than comparison peers (M = 42.83, SD = 39.63).³

Within-group Analyses
Late effects were positively correlated with past PTSS, r = .49, p < .05. Diagnosis (i.e., leukemia, lymphoma, or solid tumor), time since diagnosis, and initial treatment severity were not associated with past or current PTSD, PTSS, or A-DES scores.

Qualitative Analyses
We examined the types of traumatic events reported by participants on the K-SADS (i.e., cancer-related, intentional harm, and unintentional harm). Interview transcripts were reviewed by two authors (CAG, JMY) with 100% agreement on classification of the three categories. Of the 16 traumatic events described by survivors, five (31%) were cancer-related; seven (44%) were unintentional (e.g., car accident); and four (25%) were intentional acts of harm (e.g., witnessing rape of mother). Of the five cancer-related events, two described the entire cancer experience as traumatic, two noted painful procedures were traumatic, and one described stem cell transplant and knowing other children who died as traumatic. Of the 14 traumatic events described by comparison peers, 10 (71%) were unintentional, and four (29%) were intentional acts of harm. No peers reported trauma related to a friend or relative having an illness.

To examine whether survivors with cancer-related traumatic events had different stress reactions than survivors with traumatic events unrelated to cancer, we examined the number who reported PTSD, PTSS, and dissociative experiences for each group. Of the five survivors that reported cancer-related traumatic events, none met criteria for PTSD, and only three reported at least one PTSS (60%). Of the 11 survivors with noncancer related traumatic events, two (22%) met criteria for PTSD, and eight reported at least one PTSS (73%). The mean number of PTSS was 3.00 (range = 0–8) for cancer-related events and 5.73 (range = 0–17) for non-cancer related events. In addition, the mean A-DES scores was 18.60 (SD = 13.47) for survivors reporting cancer-related events and 44.73 (SD = 41.18) for those reporting noncancer related events.

³Overall, A-DES scores were marginally higher for participants who reported any past or current PTSS on the K-SADS (p = .06), as well as those who met A1 (p = .05) and A2 (p = .06) criteria, compared to participants who did not.
Discussion

This study compared post-traumatic stress among survivors of childhood cancer and comparison peers during the transition to emerging adulthood. We used a controlled design with reasonable recruitment rates and multimethod data collection. While our data were obtained when participants were just entering emerging adulthood, we asked about PTSD/PTSS across their lifetime as well as currently. Our data did not support the hypothesis that survivors would currently or retrospectively report more PTSD, PTSS, and dissociative events than comparison peers. Although studies have found that 15–35% of survivors meet criteria for PTSD (Pelcovitz et al., 1998; Schwartz & Drotar, 2006; Hobbie et al., 2000), many suggest that rates of past and current diagnoses or symptoms are similar to controls (Barakat et al., 1997; Brown et al., 2003; Kazak et al., 1997) or the general population (i.e., 1–14%; American Psychiatric Association, 1994; Brown et al., 2003; Kazak et al., 2004). Our findings were more consistent with the latter studies, possibly due to similarities in methodology, such as improved recruitment rates, a focus on adolescents, and the use of healthy controls.

Survivors reported lower dissociative scores compared to peers, and less than one-third of survivors who reported a trauma, reported a cancer-related event. This was equivalent to <10% of our total sample. Previous studies have often used approaches which assume a priori that: (a) cancer is a traumatic event, and (b) cancer is the most traumatic event the child has experienced. Our findings seem to indicate that the definition of a trauma may be more subjective with regard to having cancer. Because contextual factors might affect report of symptoms, we collected data in homes and did not remind participants about cancer during our assessment. This format minimized potential for a “focusing illusion” when stimuli or events that precede questions about adjustment influence the report of symptoms (e.g., Schkade & Kahneman, 1998). Methods of assessing PTSS/PTSD that emphasize a specific trauma or alternatively, structure queries in an open-ended manner both have merit and provide unique data about the adjustment of survivors. However, there is no gold standard for assessment, and further work in this area is needed (Sherburne & Radliffe, 2006). It is also feasible that cancer survivors repressed or under-reported symptoms (Hobbie et al., 2000; Phipps, Steele, Hall, & Leigh, 2001), but the lack of problems noted by caregivers is a challenge to reconcile within this framework.

The majority of survivors who reported PTSS in our study did so in relation to an accident or witnessing harm to others. The emotional impact of witnessing trauma to a loved one may partially explain why parents are often at greater risk for PTSS than survivors, particularly when children are sedated for many procedures that parents observe. One study has suggested that accident-related injuries may actually have a greater risk of triggering early PTSS in children compared to other illnesses (Landolt, Vollrath, Ribi, Gnehm, & Sennhauser, 2003). Although the authors found that rates of PTSS were not significantly different between the children who experienced an accident or cancer, PTSS was significantly associated with functional impairment, which may be important in predicting PTSS among cancer survivors.

Similar to our findings, objective medical factors (e.g., diagnosis, treatment severity) generally have not been associated with PTSS, but subjective indicators (e.g., perceived life threat/impact) may be more important (Taieb et al., 2003). The positive association found between the severity of medical late effects and past PTSS is consistent with Brown et al. (2003). It is feasible that long-term physical problems are more constant reminders of the cancer experience and contribute to the chronicity of PTSS. However, our lack of association between late effects and current PTSS suggest that these associations may have weakened by follow-up and may represent responses to current, ongoing stressors rather than post-traumatic responses.

Overall, this study suggests that survivors of childhood cancer that does not primarily affect the CNS may not be at increased risk for PTSD or PTSS during the transition to emerging adulthood. In addition, late effects may play some role in the presence of PTSS. However, our research has several limitations. First, we had power to detect only medium effects, and our methods may have lead to an under-reporting of symptoms. The optimal strategy for assessment of PTSS/PTSD is yet to be determined, but the retrospective reports obtained on the K-SADS-E are a relatively weak approach to assessing PTSD/PTSS in the past. Prospective, repeated measures are needed. In addition, our sample included some youth who relapsed after initial diagnosis, and ratings of initial treatment severity did not account for this. Obtaining cumulative severity ratings, as well as self-perception of life threat, would enhance future research. Studies that include a wider variety and age range of survivors, as well as multiple informants on other measures of PTSS also may help clarify risk for PTSS. Current treatment protocols that are under
evaluation may be useful in identifying those children and families in need of assistance (Kazak et al., 2004).

Conflict of Interest: none declared.

Received December 13, 2006; revisions received February 27, 2007; accepted April 19, 2007

References


