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## Psychosocial Late Effects in Pediatric Cancer Survivors: A report from the Children's Oncology Group

Matthew J. Bitsko, PhD<sup>1,2,\*</sup>, Debra Cohen, CPNP-BC, MSN, RN<sup>1,2</sup>, Robyn Dillon, LCSW<sup>1,2</sup>, Jeanne Harvey, RN, MSN, PNP<sup>3</sup>, Kevin Krull, PhD<sup>4</sup>, and James L. Klosky, PhD<sup>5</sup>

<sup>1</sup>Children's Hospital of Richmond, Richmond, VA 23298, USA

<sup>2</sup>Department of Pediatrics, Virginia Commonwealth University, Richmond, VA, 23298, USA

<sup>3</sup>Cardinal Glennon Children's Medical Center, St. Louis, MO, USA

<sup>4</sup>Departments of Epidemiology & Cancer Control and Psychology

<sup>5</sup>Department of Psychology, St. Jude Children's Research Hospital, Memphis TN, USA

### Abstract

**Background**—This review was conducted to update the Children's Oncology Group (COG) Long-Term Follow-Up Guidelines (COG-LTFU Guidelines; version 4.0) regarding screening for psychosocial late effects of pediatric cancer.

**Procedure**—Articles published between August 2009 and January 2011 that addressed psychosocial late effects of long-term survivors of pediatric cancer ( $n = 35$ ) were reviewed by a multidisciplinary team of COG late effect experts.

**Results**—The majority of studies in this time period indicate that survivors experience few psychosocial problems in long-term survivorship. A critical subset, however, are at increased risk for psychosocial late effects secondary to treatment. Highlighted findings from this review include increased rates of suicidal ideation (SI), and health beliefs as robust predictors of SI, anxiety, and global distress. Survivors' health beliefs were associated with their perceptions of physical limitations, overall late effects, and cancer-related pain. While many survivorship studies continue to specify risk factors for anxiety and post-traumatic stress symptoms (PTSS)/disorder (PTSD), others outcomes (e.g. developmental, interpersonal, and familial factors) appear to be emerging in importance.

**Conclusions**—Although the majority of childhood cancer survivors do not experience psychosocial problems, a subset will. The recent research findings have been included in the new COG-LTFU guidelines that will assist in the targeted assessment and treatment of survivors' psychosocial health.

\*Correspondence to: Matthew J. Bitsko, PhD, Children's Hospital of Richmond at VCU, Department of Pediatrics, PO Box 980440, Virginia Commonwealth University, Richmond, VA 23298-0440, Tel: 804-828-9048, mbitsko@mcvh-vcu.edu.

Conflict of Interests Statement

The authors report no conflict of interest.

## Keywords

Psychosocial Late Effects; Pediatric Cancer; Long-Term Follow-Up Guidelines; Children's Oncology Group

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## Introduction

Survivors of childhood cancer develop psychosocial late effects secondary to cancer and its treatment [1]. As cure rates increase and more survivors live to adulthood, anticipating and meeting this group's long-term psychosocial healthcare needs has become a priority. New challenges include developing an improved understanding of survivors' transition to adulthood [2], the implementation of new research findings in survivor assessment and intervention, and balancing favorable psychosocial outcomes with the cost-extensive resources needed by few [3]. The objectives of this report are to summarize the evidence which informed recommendations in the Children's Oncology Group (COG) Long-Term Follow-Up Guidelines (COG-LTFU Guidelines; version 4.0), outline methods of screening for psychosocial late effects of pediatric cancer, and increase awareness regarding the latest research on psychosocial functioning among survivors of childhood cancer.

This review targeted studies of psychosocial outcomes among pediatric cancer survivors who were two or more years post completion of therapy. Previous guidelines (COG-LTFU Guidelines; version 3.0) have suggested that depression [1, 4], anxiety, and post-traumatic stress symptoms/disorder [5, 6] were experienced at disproportionately high rates among survivors. Yet, current studies continue to confirm that while most survivors do well psychosocially, a subset of survivors are at increased risk for elevated distress [3, 4, 7] and poor psychosocial outcomes [8–11]. Furthermore, many positive outcomes are also seen as a result of the pediatric cancer experience, including resiliency, post-traumatic growth and benefit finding [12–14]. Incorporating these research findings into the COG-LTFU Guidelines 4.0 will facilitate clinical screening and intervention while contributing to the preventive efforts of protecting the psychosocial health of survivors.

## Methods

In 2003, COG released their first risk-based, exposure-driven guideline designed to direct follow-up care for practitioners across disciplines when caring for asymptomatic pediatric cancer survivors who are two or more years post therapy completion [15]. For the current review, multidisciplinary teams of physicians, psychologists, social workers, and nursing independently updated the COG LTFU Guidelines 4.0 for the following outcomes: Neurocognitive, Social/Quality of Life, Sleep/Fatigue, and Health Behaviors. The current authors composed the COG LTFU Psychosocial panel that developed new recommendations for the monitoring and intervention of psychosocial late effects among survivors based on the extant literature. This panel identified five broad *a priori* areas of psychosocial late effects from COG LTFU Guidelines 3.0 to guide their literature review: 1) Depression, 2) Anxiety, 3) Global Distress, 4) Resilience and Positive Growth, and 5) Developmental Barriers to Normative Adjustment. The panel was also open to new or emerging topics during the literature review, with access to psychosocial care being an example of such.

Research published between August 2009 and January 2011 was included in the current review. These dates were chosen based on the completion of the last LTFU update and ended three months post initiation of the committee's work on this project. Eligibility criteria consisted of: 1) manuscript published in a peer-reviewed journal, 2) population included survivors of childhood or adolescent cancer, 3) study abstract was available in PubMed or PsycInfo databases. Search terms used are listed in Appendix A. Literature searches were conducted and cross-reviewed by a multidisciplinary panel of late effect experts consisting of two psychologists, one social worker, and two pediatric nurse practitioners representing multiple COG sites. Bi-weekly conference calls and email communications were conducted over a 3-month period across reviewers and relevant findings were discussed. The panel member leading the review for each category completed the following tasks: a) provision of categorical references and articles one week prior to team conference call; b) provision of a summarized evidence table specific to identified articles one week prior to conference call; c) lead and facilitate a critical discussion of the presented articles during conference call; d) provide a written summary of their assigned category and recommendations for the Task Force co-chairs.

Scoring of the quality of evidence for the COG-LTFU Guidelines followed a modified version of the National Comprehensive Cancer Network "Categories of Consensus" system [16]. In short, "high-level evidence" was defined as findings derived from high quality case control and cohort studies. "Lower-level evidence" was defined as findings derived from non-experimental studies, case reports, review articles and expert opinion. Articles were further classified based on the uniformity of consensus among reviewers regarding strength of evidence and appropriateness of the screening recommendation. Final recommendations were made by the Psychosocial Late Effects panel regarding the classification of study findings into one of three categories: "confirmatory" findings of previous literature or well-established theories for this population, "disputable" evidence of issues that need further confirmatory support in the literature, and "novel" or emerging findings that need to be followed with increased methodological rigor. This is the methodology used in previous COG-LTFU Guidelines. At project completion, the leader of the multidisciplinary panel provided an overview and detailed summary of recommendations to the chairs of the Neuropsychological/Psychosocial Task Force who later summarized and presented the proposals to the COG Guideline Core Leadership Committee for potential inclusion in the upcoming version of the COG-LTFU Guidelines 4.0 (See Table I).

## Materials

Thirty five articles meeting study criteria were identified and reviewed by the panel. The 35 articles included: one randomized controlled trial, one non-randomized controlled trial, 24 of observational design (i.e. cohort, cross-sectional, or case-control), 2 studies of non-experimental design, 6 general review or meta-analytic articles, and one expert opinion. Of the 35 articles, 3 were published as part of the Childhood Cancer Survivor Study (CCSS) cohort, 4 were studies conducted with other international registries, and 4 were single institution studies with 50 participants. In addition, the articles included heterogeneous methodologies, cohorts (i.e. age at assessment and time since diagnosis), and measures used to assess psychosocial late effects.

## Results

Results of this systemic review revealed several important findings that were incorporated into the updated revision of the COG-LTFU Guidelines 4.0. These included the panels' Confirmatory findings that screening for suicidal ideation (SI) [10] and consideration of survivors' health beliefs (e.g. perceptions of physical limitations, overall late effects, and cancer related pain) as robust predictors of suicidal ideation, anxiety, and global distress – over and above provider ratings [8, 10, 11] - be included in version 4.0 (See Table I). As such, SI (under Potential Late Effects and Periodic Evaluation), Chronic pain (under Risk Factors / Medical Conditions), and Perceived poor physical health (under Highest Risk Factors / Host Factors) have been added to the list of recommendations in the COG-LTFU Guidelines 4.0 (see Figure 1). Table I also outlines findings of Disputable and Novel areas that should be considered in future research and clinical care with this population. Finally, the panel recommended several updated citations to the References section in the new Guidelines [3, 8–11] (see Figure 1).

### Depression

Overall, survivors do not appear to be at heightened risk for depression [8]. In fact, several studies have reported lower depressive symptoms for survivors compared to the general population [20, 21]. However, survivors' risk for depression may increase based on specific demographic and treatment factors, including: gender, diagnosis, age at diagnosis, unemployment, low income levels, and those reporting physical late effects of cancer therapy [3]. As such, depression is a significant issue within a limited subset of survivors.

Paramount to the current review, recent research has confirmed that a subgroup of survivors are at heightened risk for SI compared to sibling controls (7.8% vs. 4.6%, respectively, [10]), with robust associations between SI and survivor reported health, cancer-related pain, depression, and primary CNS diagnosis. This cluster of physical health, pain, and emotional concerns has previously been observed [8, 9, 22, 23]. Poor survivor-reported health was significantly associated with SI even after controlling for demographics, diagnosis and treatment factors, and depression. Interestingly, SI was not significantly associated with current age, age at diagnosis, gender, cancer therapy, recurrence or second malignancy [10]. This confirmatory finding indicates that SI and depression are distinct problems for some survivors and highlights the necessity for comprehensive assessment and treatment of SI at medical follow up. Figure 1 includes the updated COG-LTFU Guidelines 4.0 for mental health disorders.

### Anxiety Disorders

The association between a childhood cancer diagnosis and increased rates of anxiety and posttraumatic stress symptoms for survivors has been well studied [5, 6]. Prior research has elucidated that survivors who are female, unmarried, unemployed, have low household income, lower educational attainment, lack health insurance, or a chronic health condition are at increased risk for developing and maintaining an anxiety disorder [24].

Stuber [11] utilized the CCSS cohort and healthy sibling controls to compare the prevalence of post-traumatic stress disorder (PTSD). Previous research has historically assessed PTSD symptoms while rarely considering functional impairment. As such, this literature is composed of methodological heterogeneity regarding assessment modalities and a focus on either specific cancer vs. other life events, or the cumulative effect of stressful life events [25–27]. Stuber concluded that survivors had more than a fourfold greater risk of PTSD compared with siblings (9% vs. 2%, respectively [11]), while replicating many of the risk factors for PTSD noted above. Furthermore, this study found that being over age 30 and having a history of more intense cancer treatment were significant predictors of meeting full PTSD criteria [11, 28]. Survivors who experienced a relapse or recurrent disease were not at increased risk for PTSD, whereas those receiving cranial radiation at < 4 years of age were at an increased risk (OR: 2.05 [95% CI: 1.41 – 2.97]). This large study of survivors and their siblings suggests a heightened incidence of survivors who meet full PTSD criteria while clarifying the many risk factors which could be targeted for intervention within this population [11].

In contrast to the literature cited above, other research has found that adolescent and young adult (AYA) survivors do not differ significantly from controls on measures of anxiety and other psychological outcomes [8]. Most AYA survivors appear to be in relatively good psychosocial health. Among long-term survivors, however, those diagnosed during adolescence and receiving the highest treatment intensity reported relatively higher levels of anxiety and post-traumatic stress symptoms (i.e. arousal and re-experiencing) [8]. Also within this AYA sample, survivors' report of the number of their health problems was strongly and negatively associated with their psychosocial functioning. In contrast, health providers' report of the survivors' number of health problems was not correlated with psychosocial functioning. Overall, AYA survivors had less positive health beliefs (i.e. "I'm not as healthy as other people my age") than their peer controls [8]. This study confirmed the overall psychosocial health of AYA survivors, offered specific age and treatment factors associated with poor outcomes, and highlighted survivor-centered health beliefs as specific targets that providers can intervene with this population [8].

Family functioning has emerged as a salient factor in the prevalence of anxiety and PTSD for survivors [29, 30]. Recent literature has reported that 75% of adolescent survivors with PTSD (8% of sample) came from families with categorically poor family functioning [29]. Likewise a study of Japanese adolescent survivors noted the families with the poorest family functioning reported the highest levels of anxiety, post-traumatic stress symptoms (PTSS), and depression [30]. Although cross-sectional in design, these studies indicate that family functioning may be an important component of survivors' psychosocial outcomes.

### **Global Distress**

Researchers and clinicians often assess "global distress" in efforts to gain a comprehensive view of survivors' psychological functioning. For example, global distress is frequently assessed for survivors via the Brief Symptom Inventory (BSI and BSI-18; [31]). The BSI-18 is widely utilized by the CCSS and other national registries for survivors. Much of the

literature over the past several years has continued to focus and clarify the variety of medical and demographic risk factors that place survivors at risk for elevated global distress.

In accordance with the depression and anxiety literature cited above, survivors are only at increased risk for global distress when certain risk factors are present [1, 4, 7]. Risk factors included: female gender, being unmarried, being a single child, a brain tumor diagnosis, diagnosed during adolescence, and receiving more intensive treatment [3, 8]. Survivors with such risk factors often show disproportionately high rates of psychosocial distress compared to the general population (i.e. 16.9% vs. 10%, respectively) and their subjective beliefs and perceptions of their health problems correlated positively and strongly with their psychosocial distress [9]. Furthermore, many social and demographic factors appear to cascade and build over time, with lower educational attainment, being unemployed, no health insurance, and lower household income all being significant predictors of high global distress [3]. Importantly, survivors with high distress were subsequently found to have risky health behaviors (i.e. increased smoking and alcohol use) and poor health outcomes (i.e. fatigue and altered sleep) [3, 8].

### **Resilience and Positive Growth**

For many years the focus of psychosocial research has been on the perceived maladjustment during and following the cancer experience. However, as outlined above, most survivors do not have poor psychosocial functioning. Some survivors find benefit from their encounter with life-threatening illness [32] and may even experience post-traumatic growth [12].

Michel [13] recently examined how demographic and medical variables affect benefit finding in childhood cancer survivors. Survivors reported a positive relationship between benefit finding and each of the following: optimism, a leukemia diagnosis (compared to CNS and solid tumor diagnoses), and the belief that the illness still affected their lives. Results supported the use of the Benefit Finding Scale in this population and further confirmed previous studies that showed children diagnosed prior to age 5 experience less benefit finding than those diagnosed later in childhood [13]. A study of Japanese survivors found that they reported both higher rates of post-traumatic stress and higher post-traumatic growth than matched siblings [33], highlighting the notion that survivors may experience both positive and negative aspects of their illness simultaneously [34]. Other studies reported ongoing work to develop and test research tools that may be used to further our understanding of positive psychological outcomes following childhood cancer treatment; examples included the Youth Life Orientation Test [35], the Health Competence Beliefs Inventory [36], and the Impact of Cancer Scale [37].

### **Developmental Considerations and Barriers Affecting Normative Development**

The survivor population is increasing in size and lifespan, highlighting the need of this group to acquire adult skills and independence [38]. Survivors must now master skills such as normative social functioning, coping strategies, emotional development, and the formation of appropriate educational and vocational goals. Overall, an improved understanding of these developmental factors will help guide the timing, content, and intensity of future interventions [39].



One study reported that the career decision-making of Israeli childhood cancer survivors was impacted by their perceptions of vulnerability, optimism, and time perspective [40]. Two other studies from our review implemented interventions on coping and social skills for survivors. Judge Santacroce [18] demonstrated that a randomized telephone intervention was effective in delivering coping skills training to AYA survivors struggling with the uncertainty of their future health. Barrera and Schulte [17] conducted a small feasibility study focusing on a non-randomized group social skills intervention with brain tumor survivors. Results for this 8-week program showed promising recruitment, acceptability, and retention with significant improvements to parent-report of survivor's self-control, social skills, and quality of life. These are two examples of a growing literature that indicates that targeting interventions to at-risk populations during developmentally vulnerable times may be particularly effective. Given survivors' robust psychosocial health, researchers have suggested that assessing developmental struggles – such as social skills, intimate relationships [41], and vocational satisfaction – may be the most accurate measure of their current functioning, predictors of future outcomes, and should be the focus of future research and interventions [20].

### Access to Psychosocial Care

Overall, survivors struggling with psychosocial late effects of their cancer experience often receive fragmented medical and psychosocial follow up care [2]. This was an area of the literature review that was not identified *a priori* by the panel but emerged in our work. Whereas Recklitis [42] historically demonstrated that psychosocial screening can be incorporated into a survivorship follow up clinic visit, a large study of the German Childhood Cancer Registry indicated that survivors received little psychological or psychiatric care when experiencing clinically relevant symptoms of depression or anxiety (12% and 13.6%, respectively; [19]). Moreover, more than a quarter of German AYA survivors did not attend regular oncology follow-up visits [19] and only a minority of US survivors received medical care based on their previous cancer or specific risk-reduction screenings (31.5% & 17.8%, respectively; [2]). Therefore, consistent cancer-related medical and psychosocial follow-up care, especially as survivors' transition into adulthood, continues to be a significant problem for this population.

### Discussion

The COG Psychosocial Late Effects multidisciplinary panel highlighted several recommendations that have been incorporated into the revised COG LTFU Guidelines, version 4.0. Increased rates of SI among survivors indicate the need for universal screening and timely referrals by providers. While the current research on SI and survivors is sound, this clinically important area has historically been understudied. More work needs to be conducted to understand the etiology, risk-factors, and best screening/treatment practices for survivors with SI. For example, symptoms of depression and SI appear to be distinct, and need to be assessed independently. Also, current researchers [10] assessed SI by survivors' response to one item on the BSI-18. However, the clinical significance of the problem (and opportunity for risk reduction) is such that expanded and effective screening and interventions should become standard as part of survivor care [43]. The current state of

fragmented medical and psychosocial follow up for survivors throughout the lifespan is a critical issue that complicates the need for effective assessment and treatment of SI.

Our review indicates that many interpersonal factors impact survivors' emotional and physical functioning, and that survivor self-report may be the most accurate way to assess functioning within these domains. Examples include survivor self-report of poor physical functioning, extent of their late effects, cancer-related pain, and health beliefs – especially in comparison to their peers – that correlates strongly with their psychosocial functioning and is a more robust predictor of psychosocial functioning relative to provider reports [8–10]. In addition to the current practice of measuring Host, Social, and Treatment Risk Factors (see Figure 1), future guidelines should outline specific patient-reported outcomes (PRO) and psychosocial screening tools that accurately assess these risk factors and assists care planning [44, 45].

Demographic and treatment related risk-factors continue to be correlated with survivors' psychosocial functioning. For example, AYA survivors diagnosed as adolescents were significantly more likely to experience heightened global distress in survivorship than their peers diagnosed earlier in life [8]. Adolescent survivors' ability to be aware of their cancer experience (e.g. fear of death, anxiety, social and educational adjustments) from diagnosis through survivorship appears to be a developmental factor which predicts later psychosocial functioning. This highlights the need to assess both the psychosocial functioning of survivors diagnosed as adolescents and the possible effectiveness of targeting this group for interventions. Additionally, survivors who were diagnosed four years of age who received cranial radiotherapy were at a significant risk for developing clinical levels of PTSD [11]. These survivors may possess a host of physical and cognitive late effects that contribute to their psychosocial functioning in survivorship [11]. Taken together, these age and treatment intensity factors add to the previous list (e.g. education and income level, being unmarried or unemployed) that providers should specifically assess and target for intervention.

### Limitations to the Current Review

The narrow time period of manuscripts reviewed and the need to incorporate the current findings into previously established COG recommendations resulted in an update that may not fully attend to all psychosocial aspects of the childhood cancer survivor population. As such, this update and its citation list are representative and not comprehensive of all COG-LTFU Guideline recommendations. The narrow time period of review ending in January of 2011 is an additional limitation to the current guidelines.

As noted throughout, we continued to observe many methodological differences across studies. For example, various ages at diagnosis, age at assessing survivors' psychosocial adjustment, and diagnostic spread are an understandable yet continued problem within the literature that national registry studies have sought to remedy. In addition, psychosocial problems being assessed via a variety of self-report measures and the inconsistent inclusion of other diagnostic modalities (e.g. diagnostic interviews and level of functional impairment) should also be considered in the interpretation of these findings. While this review benefited from several studies of international registries [9, 19, 30, 33, 40], their generalizability and future applications across cultures may be a limitation.



## Areas for Future Research

Future researchers should use longitudinal methods with predictive or meditational models that increase our understanding of the etiology and development of psychosocial late effects of survivors. For example, it is currently unknown whether survivors who initially present with poor psychosocial adjustment at diagnosis or early in treatment continue to be the survivors with the poorest outcomes. Meditational models that assess the causality of psychosocial problems associated with demographic, social, and interpersonal correlates over time will help us understand how they unfold across the survivors' lifespan. Finally, increased depth and specificity of such late effects (vs. global distress) are needed to guide the targeted and timely interventions of the future [46].

Interventions that target and effectively treat the psychosocial late effects of survivors is the continued critical next step for behavioral health providers [3, 19, 23, 47, 48]. While much attention has been given to the many recruitment and retention barriers to these interventions [48–50], several studies serve as quality examples of their success [51–53]. Financial and programmatic restraints continue to be the largest barriers to well-powered and methodologically rigorous interventions within this population [47]. However, the failure of behavioral health providers to demonstrate robust effects in future interventions may hamper future funding opportunities, and the ability to solidify the roles of the behavioral health providers within the larger pediatric oncology health care team.

Future research should mirror our medical colleagues' focus on health outcomes for adult survivors of childhood cancer throughout their lifespan [54]. New data indicates that by age 45, survivors have a 95.5% estimated cumulative prevalence rate of having a chronic health condition and 80.5% have a serious/disabling or life-threatening chronic condition [54]. Since our current review highlights the importance of survivor-reported beliefs of poor physical functioning, extent of their late effects, cancer-related pain, and health beliefs on their psychosocial functioning, the life-long cumulative incidence of a serious chronic condition underscores the need for effective and readily available psychosocial assessment and interventions as survivors' age into adulthood.

## Conclusion

The majority of long-term survivors of childhood cancer are living longer lives with relatively few psychosocial late effects of their treatment. When psychosocial late effects are present, however, they appear to severely impact many realms of their lives. As such, there continues to be a critical subset of survivors that are in need of effective evaluation and targeted interventions that treat their psychosocial problems. It is unknown how many survivors may develop psychosocial problems later in life as the incidence of having a chronic medical condition accumulates. Importantly, these survivors access their medical care in a variety of settings (i.e. oncology specialty centers vs. the primary care setting) and during chronological ages where transitions from pediatric to adult medical providers make identification of a medical home challenging. Therefore, all potential healthcare providers must be aware of survivors' possible psychosocial late effects and effective treatment options.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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## Abbreviations

|                    |                                                                 |
|--------------------|-----------------------------------------------------------------|
| <b>COG</b>         | Children's Oncology Group                                       |
| <b>LTFU</b>        | Long-Term Follow-Up                                             |
| <b>PTSS / PTSD</b> | post-traumatic stress symptoms / post-traumatic stress disorder |
| <b>SI</b>          | Suicidal ideation                                               |

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| ANY CANCER EXPERIENCE                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |                       |                                                                                                       |                                                                                                                                                                                                                                                                                             | (CONT)                                                                                                                                                                                                      |                                                                                                                                                       |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
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| Sec #                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             | Therapeutic Agent(s)  | Potential Late Effects                                                                                | Risk Factors                                                                                                                                                                                                                                                                                | Highest Risk Factors                                                                                                                                                                                        | Periodic Evaluation                                                                                                                                   | Health Counseling/ Further Considerations                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| 2                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 | Any Cancer Experience | <b>Mental health disorders</b><br>Depression<br>Anxiety<br>Post-traumatic stress<br>Suicidal ideation | <b>Host Factors</b><br>Female sex<br>Family history of depression, anxiety, or mental illness<br><b>Social Factors</b><br>Lower household income<br>Lower educational achievement<br><b>Treatment Factors</b><br>Hematopoietic Cell Transplant<br><b>Medical Conditions</b><br>Chronic pain | <b>Host Factors</b><br>CNS tumor<br>CNS-directed therapy<br>Premorbid learning or emotional difficulties<br>Perceived poor physical health<br><b>Social Factors</b><br>Failure to graduate from high school | <b>HISTORY</b><br>Psychosocial assessment with attention to:<br>- Depression<br>- Anxiety<br>- Post-traumatic stress<br>- Suicidal ideation<br>Yearly | <b>Health Links</b><br>Emotional Issues<br><b>Resources</b><br>'Childhood Cancer Survivors' by Nancy Keene, Wendy Hobbie & Kathy Ruccione, Childhood Cancer Guides, 2012<br><b>Considerations for Further Testing and Intervention</b><br>Consider psychological consultation in patients with emotional difficulties related to cancer experience, including physical deformities or chronic disabilities. Consider appropriate psychotropic medications. Consider evaluation of parent for post-traumatic stress syndrome<br><br><b>SYSTEM = Psychosocial</b><br><b>SCORE = 2A</b> |
| <b>SECTION 2 REFERENCES</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |                       |                                                                                                       |                                                                                                                                                                                                                                                                                             |                                                                                                                                                                                                             |                                                                                                                                                       |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
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**Figure 1.**  
From the Children’s Oncology Group Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent and Young Adult Cancers, Version 4.0, October 2013, used with permission.



**TABLE I**  
**Summary of Findings: Psychosocial Late Effects**

Children's Oncology Group, Long-Term Follow-Up Guidelines, Version 4.0

| Level of Findings | Findings                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
|-------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1. Confirmatory:  | Survivors generally have similar psychosocial outcomes compared to controls. Subsets are at increased risk for: <ul style="list-style-type: none"> <li>• Increased suicidal ideation associated with increased depression, poorer physical health, cancer-related pain, &amp; primary CNS diagnosis [10].</li> <li>• Poor psychosocial functioning and lower beliefs of health and well being are associated with self-reports of health problems [8].</li> </ul>                                                          |
| 2. Disputable:    | Treatment intensity associates with psychosocial outcomes: <ul style="list-style-type: none"> <li>• Intensive treatment associated with increased risk of meeting full PTSD criteria [11].</li> <li>• Intensive treatment and adolescent age at diagnosis associated with increased anxiety and fewer positive beliefs of health and well-being [8].</li> </ul>                                                                                                                                                            |
| 3. Novel:         | <ul style="list-style-type: none"> <li>• Of survivors experiencing clinically relevant anxiety, depression, or PTSS, only 12.0% are receiving psychological care, and 13.6% are reporting use of psychotropic medications [19].</li> <li>• Among survivors, poor familial functioning is associated with increased anxiety, depression, PTSS, and PTSD [29,30].</li> <li>• Promising findings of a piloted RCT examining a telephone-based coping skills intervention in improving psychological outcomes [17].</li> </ul> |

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