Published in final edited form as:
Pediatr Blood Cancer. 2015 December ; 62(Suppl 5): S514–S584. doi:10.1002/pbc.25783.

Psychosocial Follow-Up in Survivorship as a Standard of Care in Pediatric Oncology

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Abstract

Childhood cancer survivors (CCS) have a high risk of medical late effects following cancer therapy. Psychosocial late effects are less often recognized. Many CCS do not receive long-term follow-up (LTFU) care, and those who do are rarely screened for psychosocial late effects. An interdisciplinary team conducted a systematic review of qualitative and quantitative studies to assess social, educational, vocational, psychological, and behavioral outcomes along with factors related to receipt of LTFU care. We propose that psychosocial screening be considered a standard of care in long-term follow-up care and that education be provided to promote the use LTFU care starting early in the treatment trajectory.

Keywords

long-term follow-up care; survivorship; childhood cancer; psychosocial

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Conflict of Interest: Nothing to declare.

Author Contributions

This work was conducted collaboratively as part of the *Standards for Psychosocial Care of Children with Cancer and their Families* Workgroup. E.A.L. and B.J. were responsible for the conception and design of the proposed standards in this manuscript. F.P. was responsible for the initial literature search and collection and assembly of data. E.A.L., F.P., L.A.S., and A.R.R. conducted supplementary searches. E.A.L., F.P., L.A.S., and A.R.R. wrote sections related to each standard and E.A.L., A.R.R., and B.J. did final editing including final approval of data analysis, interpretation, and presentation of data, and completed critical revisions for important intellectual content. All authors approved of the final version of this manuscript and take public responsibility for the content presented in this article.

Financial Disclosure

The authors have no financial relationships relevant to this article to disclose.

INTRODUCTION

Rapid improvement in treatment for child and adolescent cancers has led to greatly increased survival with a growing population of over 300,000 long-term childhood cancer survivors (CCS) in the United States.[1] Sixty percent of CCS report medical morbidities.[2–4] Long-term follow-up (LTFU) care is recommended and involves systematic assessment to detect and treat health problems related to childhood cancer and its treatment.[5] However, late effects of childhood cancer are not limited to physical health problems. Previous studies describe CCS as having psychosocial difficulties impacting academic achievement, employment, social, and family relationships,[6–15] affective distress,[16–18] posttraumatic stress symptoms,[19–21] suicidality,[22] and tobacco and heavy alcohol use.[23,24] Few survivors receive dedicated LTFU care,[25–29] and even fewer receive a comprehensive psychosocial assessment.[30]

The Children’s Oncology Group (COG) has outlined LTFU guidelines that provide recommendations for regular surveillance and care for those 2+ years from end of treatment based on specific treatment exposures.[31,32] The COG LTFU guidelines are updated periodically using systematic reviews of published scientific literature. While guidelines primarily pertain to physical late effects, recommendations also include screening for psychological, social, and behavioral difficulties.[31] This manuscript builds on the COG recommendations and provides an additional, updated review of the recent literature focusing on the psychosocial sequelae from childhood cancer and the psychosocial factors influencing uptake of LTFU care. The goal of the review is to identify and summarize the evidence so that screening can target the most relevant psychosocial domains. Screening for distress among cancer survivors has been recommended starting at cancer diagnosis and at appropriate intervals thereafter.[33–35] The provision of screening supports patients’ wishes since psychological well-being has been described by CCS as more important than physical quality of life (QoL) dimensions.[36]

METHODS

This review was performed as part of the collaborative *Standards for Psychosocial Care of Children with Cancer and Their Families* effort. For a full description of the methods used to develop each standard, please refer to Wiener et al.[37] Search terms specific to this manuscript included “education,” “vocation,” “depression,” “anxiety,” “tobacco,” “alcohol,” or “long-term follow-up.” (The full list of search terms is available in Supplemental Table I.) The search identified 813 articles of which 93 met inclusion criteria and were reviewed. (See Supplemental Figure I, PRISMA.) These articles included six systematic reviews, three narrative reviews, one case-control, 67 cross-sectional/cohort or retrospective chart reviews, 10 qualitative and four mixed methods studies, one opinion piece, and one randomized trial. Studies were published January 2011 to April 2015, supplementing the COG LTFU guidelines, Version 4.[31] Inclusion criteria were: CCS (i) diagnosed between ages 0–18; (ii) completed treatment for initial cancer diagnosis; and (iii) psychosocial issues were key outcome measures. Studies were excluded when CCS data were aggregated with adult cancer survivors, main outcomes were focused on measurement validation or interventions, except where unique data on psychosocial factors was provided. Additional articles were identified through references in the included articles, and by group consensus. Standards were developed following a lengthy procedure as outlined in Wiener et al.[37] adhering to suggested methods for guideline development in the existing literature.[38,39] The goal of the paper was to document the type and extent of psychosocial issues in CCS in order to develop recommendations that can be applied across all cancer treatment centers and begin the process of addressing CCS psychosocial issues.

The study team includes epidemiologists (EAL and ARR), social workers (FP and BJ), a psychologist (LAS), an oncologist (ARR), and a stakeholder (EAL). A nurse and a social worker with CCS specialization externally reviewed drafts of the manuscript.

RESULTS

Table I summarizes findings from the literature review. In general, studies describe most CCS as well-adjusted; however, studies have described poorer psychosocial outcomes compared with the controls.

Social, Academic, and Vocational Difficulties

CCS may be at risk for social and relationship difficulties. For example, CCS who participated in the 2009 U.S. Behavioral Risk Factor Surveillance Study (BRFSS) were significantly more likely to report poor social support compared with their peers.[40] Reports from the Italian, Swiss, and U.S. Childhood Cancer Survivorship Studies (CCSS) described lower marriage rates among CCS compared with the population controls and data from the U.S. cohort suggested CCS have poorer sexual health.[13–15,41]

Educational and vocational disadvantages are also reported in CCS. Although some CCS report greater school satisfaction than controls,[42] CCS generally have lower educational attainment.[15,43–45] Likewise, they are less often in high skilled managerial or professional positions, less likely to work full-time, receive lower incomes than their gender-matched siblings,[46] and are more likely to be unemployed.[15,47] Survivors of Wilms tumors are slightly less likely to go to college or obtain employment.[43] Brain tumor survivors are at risk for poor vocational outcomes;[47] however, special education programs can minimize these disparities.[15] Hence, early detection and referral for services has potential to improve patient outcomes. Risk factors for social, academic, and vocational difficulties include diagnosis or treatment for central nervous system (CNS) tumors, premorbid learning or emotional difficulties, low income or education, hematopoietic cell transplant, and younger age at diagnosis.[31]

Mental Health Concerns

Systematic and narrative reviews describe CCS as experiencing lower psychological well-being, greater anxiety, more problem behaviors, and more PTSS.[48] Brain tumor survivors report greater depression, anxiety, suicidal ideation, and behavioral problems.[49] Studies of acute lymphoblastic leukemia survivors report higher risk for adverse psychological outcomes such as depression and somatic distress.[15]

Large, high-quality studies including the CCSS from the U.S. and Switzerland, the U.S. BRFSS, and the Danish Cohort study provide evidence of greater mental health distress,[50] greater utilization of mental health care,[47,51] greater risk for neurodevelopmental, emotional, and behavioral disorders,[52] more psychoactive medication use,[53] suicidal ideation,[54] and higher rate of posttraumatic stress in CCS compared with sibling controls.[55] In a study comparing CCS to healthy peers, CCS reported more days per month of poor mental health.[40] A longitudinal study noted worsening physical health predicted greater depression, anxiety, and somatization.[56] Some large studies report no differences in mental health outcomes between CCS and siblings,[57,58] and no differences in anxiety and depression scores between CCS and population controls.[59] Negative outcomes are generally associated with a diagnosis or treatment for CNS tumors, premorbid learning or emotional difficulties, perceived poor health, female gender, and low socioeconomic status.[31]

Risky Health Behaviors

Compared with a representative sample of matched peers, smoking is more common among adult CCS and use of smokeless tobacco is more common among a sub-sample non-white men aged 35–49.[40,60] As a whole, CCS are less likely to engage in smokeless and dual tobacco use (smokeless and combustible).[60] Past month and binge drinking is not significantly different between adult survivors and controls.[40] In adolescent CCS, tobacco and alcohol use is comparable to siblings though current beer/wine consumption, binge drinking, and smokeless tobacco use in adolescent CCS.[61] Lower household income or education and older age at diagnosis increase risk for risky health behaviors.[31]

Psychosocial Associates of Engagement in Long-Term Follow-Up Care

Our search methods did not identify evidence-based practices to promote ongoing LTFU care for CCS or youth transition to LTFU care in the adult system. Patient-provider communication about health risks and follow-up care may be important to sustain engagement in care and uptake of recommended screening.[62] Cancer-related anxiety and perceived poor health status relates to the likelihood of having conversations about risk-based care and screening.[62] Hypothesized psychosocial factors that impact uptake of follow-up care and readiness to transition to adult care include patient knowledge/perception of late-effects, feelings of health vulnerability, motivation to pursue follow-up care, and disease self-management.[63–66] Cancer identity and emotional components such as fear, gratitude, and gaining perspective positively influenced likelihood of transition to adult care.[67]

DISCUSSION

While results from the systematic review show that many CCS are able to adjust and move beyond their cancer experience, psychosocial difficulties are also widely described. Findings from the present systematic review are consistent with previous studies. Our review supported prior reports that CCS have lower educational and vocational attainment compared with the controls.[2] Screening for needed educational support during and after cancer treatment may minimize this disparity.[15] A pattern of greater psychosocial distress, [2,17,68,69] (but not greater psychopathology [70]) in CCS compared with controls was also supported in this review.

Reports that PTSD is more common among CCS may be partially explained by methodological differences.[71–73] For instance, lower rates of PTSD are reported when authors employ stricter criteria for diagnosis, or direct the focus on the cancer as the sole traumatic event.[71,74] Full coverage of the PTSD debate falls outside the scope of the present review. However, because considerable debate remains in the field about whether there is additional risk for PTSD among CCS, the authors have not included such screening in the proposed standards. As more definitive studies clarify the traumatic impact of childhood cancer, screening recommendations should be revisited. Previous studies described tobacco or heavy alcohol use as comparable or slightly lower among adult and adolescent CCS compared to peers or siblings.[23,24,75–77] Unfortunately, tobacco and heavy alcohol use is not lower in the most medically vulnerable CCS.

To combat underrecognition and undertreatment of psychological problems in CCS, a first step involves systematic screening to accurately identify those who most need support. [31,35, 78–80] To be effective, screening must be paired with referral for support, education, and treatment as appropriate. Evidence-based interventions to address psychosocial late effects have been described elsewhere.[81,82] CCS with risky health behaviors rarely receive risk-based medical care.[83]

A recent systematic review described psychosocial screening tools for CCS such as those to assess overall distress,[86] depression, anxiety, and suicidality.[84,87–90] Strong recommendations exist for the use of brief screening tools to identify substance use in primary care settings for healthy adults and adolescents.[93,95] Use of these tools has been shown to be effective in reducing problematic drinking and tobacco use when combined with brief interventions in healthy populations.[76,96,98–100] It is recommended that substance use screening occur in the LTFU setting, in addition to primary care, given synergistic health risks for CCS related to treatment exposures. Providers of LTFU care are likely more attuned to these specific health risks. Delivery of interventions that employ survivor focused counseling have been shown to be more effective in reducing smoking among CCS though substance use treatment remains challenging for survivors, as for other populations.[101,102]

With the development of more effective treatments the population of CCS has grown and so too has the number of survivors suffering from psychosocial sequelae. Psychosocial screening in LTFU settings is effective in identifying distress and CCS report minimal burden and high acceptance.[103, 104] In the absence of data on the most effective screening schedule, practical considerations influence the recommendation that screening should be administered according to existing COG LTFU schedules for care (usually yearly based on exposures) and performed for all survivors, regardless of diagnosis or exposure.[31] CCS who consistently screen negative for substance use could receive reduced screening over time consistent with healthy population data showing declining initiation of substance use with age.[105] Larger studies are needed to describe the implementation and adequacy of specific psychosocial screening instruments in a variety of LTFU care setting [84] and thus future research should identify appropriate, sensitive, and acceptable brief instruments for CCS.

Some authors have questioned the utility of screening and suggested that energies could be put to more productive use in treating distress.[106–110] Screening may improve patient-provider communication,[111,112] but there is not clear consistent evidence that it improves survivor well-being.[113–116] Questions remain on what should be screened, how screening should be implemented (on-line, in-person, nurse vs. doctor), whether to assess felt need or contextual need, and what to do with the results.[117] The addition of information on the context of the distress may reveal need for concrete support rather than psychosocial support. Certainly, screening is unlikely to be effective unless is leads to a response, whether that is further clinical assessment, treatment, or just an acknowledgement of the distress. More research is needed to discern the best methods for screening.[117]

Many survivors are not worried about their health,[118] underestimate their health risks,[63,64,119] know few details of their treatment history,[119] and few engage in detailed discussions about their cancer history with a provider or receive regular cancer specific follow-up care [118] creating a barrier to psychosocial screening.[31,120] Less than 20% of adult CCS reported follow-up care that included advice about risk reduction, or screening tests for physical late effects.[26,121] Patient and parent education that starts early in the treatment trajectory and emphasizes the importance of LTFU is needed. Furthermore, primary care providers and other adult health care providers may need focused education about both the physical and psychosocial sequelae of childhood cancer, and published guidelines must emphasize both realms of whole-patient care.[122]

Certain barriers have been identified and include lack of financial or personnel resources, lack of health insurance reimbursement or psychosocial providers, or low motivation for screening. These barriers may be addressed by use of brief standardized instruments, development of hospital and community referrals, and provider education. Future research must focus on the selection, timing, and efficacy of such screening tools in CCS.[123]

A number of limitations exist in the manuscript. We chose to target specific negative psychosocial late effects most often identified in the literature. We did not include studies assessing global or abstract constructs such as QoL, neurological, or cognitive late effects (addressed within this special issue [124]), or positive outcomes, though promoting such outcomes may contribute to survivor well-being and QoL.[125,126] A full review of assessment instruments and effective interventions for each outcome was beyond the scope of the project and is reviewed elsewhere.[81,82] Finally, given the considerable presence of psychological late effects in CCS, the authors recommend screening while recognizing that future research is needed to determine whether screening lessens this morbidity.

In summary, the burden of chronic health problems among CCS is profound in both prevalence and severity.[127] Receipt of LTFU care that addresses both physical and mental health sequelae of childhood cancer is critical to supporting longevity and well-being.[128] In the face of late medical health effects, some of which are not reversible, health care providers can still attend to the human cost of cancer by asking the patient about his or her experience and listening to the answer.[128]

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

Authors would like to thank stakeholder groups who conducted external reviews of this work.

Abbreviations

CCS	childhood cancer survivors
CNS	central nervous system
COG	Children's Oncology Group
HRQoL	health-related quality of life
LTFU	long-term follow-up
PTSD	post-traumatic stress disorder
QoL	quality of life

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Psychosocial Standard of Care

- Long-term survivors of child and adolescent cancers should receive yearly psychosocial screening for: (1a) adverse educational and/or vocational progress, social and relationship difficulties; (1b) distress, anxiety, and depression; and (1c) risky health behaviors.
- (2) Adolescent and young adult survivors and their parents should receive anticipatory guidance on the need for life-long follow-up care by the time treatment ends, and repeated at each follow-up visit.

TABLE I

Psychosocial Follow-Up in Survivorship-Summary of Literature

Standard	Evidence summary	Methodology	Quality of evidence	Strength of recommendation
1. Long-term survivors of child and adolescent cancers should receive yearly psychosocial screening for:				
(a) Adverse educational and/or vocational progress, social and relationship difficulties;	Subsets have impaired social relationships, lower educational and vocational attainment, and impaired QoL due to psychological distress, medical late effects, or financial hardship. Multiple studies highlight identifiable and possible modifiable risk factors for poor QoL in CCS.	Cross-sectional survey-based, descriptive, and qualitative studies were most common; several large survivorship cohort studies included. Few systematic reviews of descriptive studies; no experimental or quasi-experimental studies. Broad range of selected variables examined QoL.	Moderate: consistent findings from lower level evidence studies.	Strong: Recommendation applies to most patients in most circumstances, low risk and high benefit associated with guideline with potential health benefit for CCS and family. Further research needed to increase confidence in the estimate of effect and to inform future interventions.
(b) Distress, anxiety, and depression;	Subsets of CCS are at higher risk for poor mental health outcomes, especially survivors of CNS tumors.	Systematic reviews, cross-sectional survey-based, cohort, qualitative, and mixed methods studies. Many large survivorship cohort studies with controls are included of descriptive studies.	High: consistent findings from multiple studies with large cohorts. More longitudinal studies are needed.	Strong: Recommendation applies to all survivors, low risk and high benefit associated with guideline and potential health benefit for CCS. Future longitudinal research could better identify trajectory of distress and critical opportunities for intervention.
(c) Risky health behaviors.	Heavy alcohol use, smoking, smokeless tobacco and dual tobacco use are similar or lower in CCS compared with peers or national norms. Some of the most medically vulnerable groups smoke and drink similarly to peers.	Five of the seven studies were cross sectional, several with large samples and controls. One case-control design and one systematic review (COG) citing additional studies with strong methodology.	High-moderate quality of evidence. Studies identified sub-groups at risk.	Strong: Recommendation applies to all survivors. Low risk associated with guideline, high potential health benefit given possible synergistic health risks for CCS. Brief screeners exist but future research needed to test them in CCS population.
2. Adolescent and young adult survivors and their parents should receive anticipatory guidance on the need for life-long follow-up care by the time treatment ends, and repeated at each follow-up visit.	Psychosocial variables impact uptake of follow-up care and readiness to transition to adult care. These include patient knowledge/perception of late effects, vulnerability, motivation to pursue follow-up care, and disease self-management/self- efficacy.	Cross-sectional cohort, qualitative (focus groups and interviews), opinion	Low to moderate: evidence for critical outcomes, from observational and cross-sectional studies.	Strong: Recommendation applies to most survivors. Future research should assess the impact of transition readiness and receipt of LTFU care on long-term outcomes of CCS.

CCS, childhood cancer survivors; PTSD, post-traumatic stress disorder; CNS, central nervous system; HRQoL, health related; COG, Children's Oncology Group; LTFU, long-term follow-up.