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Advances in Pediatric Psycho-Oncology

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Structured Abstract:

Purpose of review—This article reviews the current literature on psychosocial care of children with cancer with particular focus on evidence-based standards of care, including developments in systematic distress screening, utilization of patient-reported outcomes, evidence-based interventions, survivorship, palliative care and bereavement.

Recent findings—While attention to the psychosocial needs of the child and family is increasingly recognized as an essential element of care for children with cancer, implementing evidence-based care remains suboptimal. Recent efforts have focused on utilizing technology to improve the reach of these interventions and to enhance engagement with populations such as adolescents and young adults. Increasing data elucidate the long-term psychological and physical late effects of childhood cancer survivorship and the impact of cancer on siblings and the family. Gaps in clinical care and important directions for future research include the needs of infants and toddlers, overlooked minorities, and patients with hereditary tumor predisposition syndromes, and attention to the psychosocial impact of exciting new treatments such as autologous chimeric antigen receptor (CAR) T cell therapy.

Summary—The evidence base for the psychosocial standards of care for children with cancer and their families continues to grow, but more work is needed to successfully implement these standards across pediatric cancer centers.

Keywords

Pediatric; psychosocial; assessment; adaptation; standards

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Conflicts of interest

None

Introduction

Comprehensive care for the child with cancer and family requires a focus on the short and long-term quality of life of the children, their siblings, and immediate family members. Successful outcomes hinge on the provision of detailed assessments and tailored interventions. These should be provided from diagnosis through survivorship or bereavement with a focus on adaptive coping and the prevention of medical trauma and physical, neurocognitive and psychosocial late effects. Such care is best provided by an integrated, collaborative, interdisciplinary healthcare team [1].

Psychosocial clinicians are challenged to standardize their approach and evaluate efficacy of their clinical efforts. To ensure that children with cancer and their family members receive the psychosocial care they need, an interdisciplinary group of pediatric oncology psychosocial professionals, experts, and stakeholders developed 15 evidence- and consensus-based standards [2]. This is a major advance, as psychosocial standards can systematize the approach to care and create a replicable model to be used in pediatric hospitals around the world [3]. Information about these standards are integrated throughout this paper along with new research findings pertaining to screening, evidence-based interventions, family impact and palliative care that have the potential to advance the field of pediatric psychosocial oncology.

Systematic screening and patient-reported outcomes

Early and repeated screening allows for the identification of patients and families with high psychosocial risk and for targeted delivery of available evidence-based interventions. Currently, two reliable, well-validated, and evidence-based tools exist for screening in pediatric oncology, the Psychosocial Assessment Tool [4] and the Distress Thermometer [5]. Although routine psychosocial screening is endorsed by several prominent organizations (e.g., Institute of Medicine, National Comprehensive Cancer Network, and the American Psychosocial Oncology Society) and has been established as a standard of psychosocial care [6], clinical implementation within pediatric oncology settings is still rare [7, 8**]. Recent research has identified barriers to screening, including lack of institutional support and resources, limited knowledge of existing evidence-based screening tools, concerns about tool applicability across diverse family cultural backgrounds, and practical implementation issues such as staff training, integration of findings into clinical care workflows, and logistics of completion [9*, 10**]. These barriers have been challenged, however, by studies of feasibility, implementation, and integration into multiple clinical care settings [4, 10**, 11], which have generally found screening to be brief, acceptable, non-stigmatizing, and of low burden to patients, families, and staff.

In addition to evidence-based distress screening, there has been increased attention to routine assessment of patient-reported outcomes (PROs) throughout the cancer trajectory. PROs provide the patient and family's perceptions of physical, emotional, social, and cognitive functioning. Recent work has demonstrated the validity and sensitivity to change of Patient-Reported Outcomes Measurement Information System (PROMIS) pediatric measures for children with cancer across a number of symptom, emotional, functional, and

performance domains [12**, 13*]. These results, combined with the option to use computer adaptive testing or standard short forms, make the PROMIS measures strong candidates for routine assessment of PROs in research and practice. While most healthcare providers recognize the importance of routinely assessing PROs, barriers to doing so include time, insufficient staff, logistics, and financial resources [14]. Electronic PRO collection systems are acceptable to patients and families and may overcome some of these barriers [15*].

New approaches to screening and PRO assessment are currently in development and may facilitate clinical uptake [16]. Larger implementation trials are important, and additional research is needed on outcomes associated with screening and PRO implementation and on the optimal timing of assessment, as re-assessing at key transitions in care is likely important.

Utilizing evidence-based interventions at diagnosis and through treatment

Most pediatric centers in the United States report providing psychosocial support through informal discussion rather than evidence-based strategies, and either when a problem is identified or at diagnosis/during early treatment rather than throughout the treatment trajectory [8**]. Low uptake of evidence-based strategies may be due in part to lack of sufficiently trained staff and the burden of additional visits for patients and families to receive intervention sessions. To address these issues, there has been movement towards adapting evidence-based face-to-face interventions to electronic modes of delivery to enhance the acceptability and potential reach of these tools. For example, Canter and colleagues adapted the evidence-based Surviving Cancer Competently program to a self-guided online program with telehealth phone calls with a mental health provider [17*]. Sahler and colleagues adapted Problem-Solving Skills Training (PSST), an evidence-based cognitive behavioral therapy designed to improve constructive coping skills in caregivers of children recently diagnosed with cancer [18], for online delivery. A RCT showed significant benefits of the online intervention, but it was not equivalent to face-to-face administration [submitted paper: (Phipps S, Fairclough D, Noll RB, et al., unpublished data)]. The optimal balance of online and healthcare provider contact requires further research, and likely varies by individual needs, preferences, and timing of the intervention.

A number of new interventions have recently been developed to address specific issues or special populations, often incorporating evidence-based strategies or using technology to engage patients and families. For example, a feasibility study of an interactive humanoid robot to decrease procedural pain demonstrated promising initial results among younger children [19]. For adolescent and young adult patients newly diagnosed with cancer, a brief skills-based intervention was found to improve resilience and cancer-specific quality of life, as well as reduce distress [20*].

Children with brain tumors remain one special population with high psychosocial needs but few available evidence-based interventions. One recent study found that a novel year-long musical training intervention improved symptoms of depression and enhanced self-esteem and quality of life [21]. Another study of computerized working memory training with or without parental problem-solving skills training found many barriers to implementing this

type of intervention with brain tumor survivors and their families due to the time commitment and intensity of the training [22]. Altogether, definitive efficacy testing is needed for novel interventions.

Impact on Family

It is widely recognized that a cancer diagnosis impacts the psychosocial functioning of the entire family. Recent data confirms the negative impact of a child's cancer diagnosis on parents' health-related quality of life and overall marital adjustment [23, 24, 25*]. Hospitalizations, relapses, and the transition off treatment have been found to be particularly stressful time points for caregivers and their relationships [24, 26]. Furthermore, factors such as economic strain, frequent treatment-related and negative life events, and cumulative stress have been associated with poorer marital adjustment over time [23]. While couples indicate an interest in counseling as a means to support their relationship [24] and access to appropriate interventions for parents and caregivers is supported as a standard of care [27], evidence-based interventions are not always routinely available due to lags in dissemination and site-specific resource limitations [7]. Progress has been made, however, with widespread and systematic dissemination of interventions like PSST [18]. Finally, recent literature has focused on 'lone' parents (i.e., those who feel alone when caring for a child with cancer, regardless of marital/partnership status) [28, 29*]. Lone parents have been found to report increased financial concerns, less emotional support, higher global distress and decreased ability to meet their children's basic needs compared to non-lone parents. Better understanding of the 'lone' parent may allow for more accurate identification of parents who are at increased psychosocial risk.

Like caregivers, siblings are at risk for poor psychosocial outcomes in some domains. In an updated systematic review on the psychosocial functioning and risk factors among siblings of children with cancer [30**], levels of anxiety, depression, and general adjustment were similar across siblings and comparisons, but symptoms of cancer-related posttraumatic stress were prevalent. Recent sibling studies suggest that patients and parents appear to be aware of and concerned about siblings' challenges [31], that a group intervention may be most effective for siblings with depressive symptoms [32*], and that an inpatient family-oriented rehabilitation program including healthy siblings can be effective in improving knowledge about cancer, self-reported emotional symptoms, and parent-proxy-reported symptoms [*9].

Overall findings indicate the importance of identifying at-risk siblings (including sibling donors of bone marrow [33, 34]). Interventions are needed, however, to facilitate family communication and increase siblings' social support, cancer-related knowledge, and treatment involvement [35]. A better understanding of the mechanisms and moderators of siblings' adjustment would inform timing and targets of psychosocial care throughout the cancer trajectory, including bereavement [30**].

While the emotional toll of a child's cancer diagnosis on the family is well understood, recent data have also confirmed the devastating economic impact [36, 37*, 38**]. Direct medical costs, especially for families with limited insurance coverage, is only one piece of the financial burden. Utilizing multiple measures of family-reported financial burden, recent

studies have found between 15 to 30 percent of families with a child undergoing cancer experience food, housing, or energy insecurity, which increases from diagnosis through treatment and into the off-therapy period [38**, 39, 40]. Considering the long-lasting chronic health conditions and cumulative psychosocial burden of surviving childhood cancer [31], financial hardship requires significant attention. The development of assessment tools and intervention strategies, particularly for low income families who are at greatest risk, represents an important area for future investigation [40, 41].

Survivorship

Numerous studies continue to elucidate the long-term psychological and physical late effects of childhood cancer survivorship. Most recently, studies have focused on health behaviors [42, 43], sleep [44], fertility issues [45, 46], and psychological adjustment, distress, and unmet needs [47–52]. In the past year, there has been particular focus on adolescent and young adult survivors transitioning from active treatment into survivorship [53], with feasibility studies utilizing videoconferencing to assist adolescent and young adults during this transition [54, 55*] and a meaning-based photograph intervention on a closed social media platform [56*]. Results indicate these interventions are acceptable, though adolescents and young adults are a difficult group to engage, and larger efficacy trials are needed.

Recent work has highlighted the significant needs of adolescent and young adult survivors as they transition from pediatric to adult care. These survivors have poor knowledge of their late effect risks, which is associated with lower levels of responsibility for healthcare self-management [57]. A small randomized trial found a text-message based intervention improved survivorship care knowledge compared to standard educational materials, while a peer navigator intervention improved survivorship self-efficacy [58*]. Another novel mobile application with a survivorship care plan and text message-based self-management intervention is currently being tested to address gaps in knowledge and self-management for this group [59*].

Advances in Palliative Care and Bereavement

Several papers have been published pertaining to adolescent and young adults' understanding of their prognoses and preferences for care, emphasizing that the desired level of involvement in decision-making may change over time [60, 61]. Data supporting the engagement of adolescents and their family members in conversations around goals of care [62] and advance care planning (ACP) have been associated with important outcomes including greater understanding of end of life wishes, fewer physical symptoms and decreased suffering [63], reduced anxiety [64], and improved congruence of stated goals of end-of-life care. Preliminary results from a study assessing the effects of using an ACP guide developed for adolescents and young adults (Voicing My CHOICES™) indicates that adolescents talk less about their preferences for care with their providers than their friends and family members, preferring that providers raise these issues with them, rather than the other way around [64]. Additional training for providers and empirical studies pertaining to outcomes of open communication are needed. A stronger evidence base will inform the

development of interventions that improve communication, bolster the clinician-parent relationship, and enhance the quality of life of children and their family members from the time of diagnosis through survivorship or end of life, and into bereavement [65].

Available survey data indicates that bereavement care of families after the death of a child from cancer is highly variable and inconsistent [66]. Few facilities report a standard approach to support bereaved families or the use of formal assessment tools to evaluate bereavement needs. Developing institutional bereavement care guidelines can facilitate consistency in services provided [67]. Training of interested multidisciplinary staff may be helpful, and use of newly developed tools should be incorporated to assess bereavement needs (e.g., Bereaved Cancer Needs Inventory [68*]), level of risk (Bereavement Risk Inventory and Screening Questionnaire [69]), and grief symptoms in surviving children (Hogan Inventory of Bereavement [70**]). Although most families will not seek formal therapy, parents with prolonged grief reactions may benefit from brief meaning-centered grief therapy [67]. More research is needed in the area of individual therapy for bereaved children who experience persistent and intense grief symptoms that cause impairment in daily functioning.

Future Directions

The development and implementation of Standards of Psychosocial Care demonstrates the remarkable growth of the field, but many new challenges await. Recent findings on special populations like infants and toddlers [71, 72*], overlooked minorities (e.g., lesbian, gay, bisexual, and transgender adolescents and young adults [73*]), and patients with hereditary tumor predisposition syndromes [74*] point to gaps in clinical care and important directions for future research. As the field moves toward more personalized and precision medicine, additional research is needed on patient and family understanding and psychosocial outcomes, including potential harms (e.g., emotional distress) and benefits (e.g., guiding of healthcare delivery) of predictive genetic testing [74*, 75*]. Ongoing attention to and collaboration with our global partners will be key to continued understanding of the psychosocial impact of childhood cancer in developing nations [76*, 77*, 78].

The remarkable success of autologous chimeric antigen receptor (CAR) T cell therapy has renewed hope for children and young adults with relapsed and/or refractory CD19+ acute lymphoblastic leukemia. Currently, anti CD19 CAR T-cell therapy is the only FDA approved CAR therapy for children, yet other CAR-T cell trials are ongoing for ALL and solid tumors [79]. While CAR T is a notable advancement in the care of a vulnerable group of patients, it is also associated with unique clinical and psychosocial challenges and often with severe toxicities. As such, careful evaluation of patient and family expectations and understanding of the potential benefits and associated toxicities should occur before leukapheresis is performed, and close baseline assessment and monitoring of the child's mental health and neurological status before, during, and after treatment is important due to the risk of rapid neurological deterioration. As with all other cancer directed therapy, interdisciplinary care is imperative to ensuring optimal patient outcomes, especially as these therapies transition from experimental research protocols to standard care [80**].

Conclusion

Psychosocial care and interventions designed to improve the quality of life of children with cancer and their family members are now routine to the medical care of children with cancer. Implementation of evidence-based psychosocial standards along with the measurement of their outcomes could dramatically move the field forward. Novel implementation delivery modalities (e.g., eHealth interventions) and multisite collaborative studies provide the opportunity to expand the reach of evidence-based interventions. A movement toward patient-engaged research also provides the opportunity to partner with families to set research agendas that truly meet their needs at different points along the cancer trajectory [81]. With various evidence-based psychosocial assessment and interventions available for children with cancer and their families, the focus of pediatric oncology research and practice should now shift to the translation of research results into practice [82].

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* of special interest

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KEY POINTS

- The Standards of Psychosocial Care are a major advance in pediatric psychosocial oncology.
- A number of evidence-based assessment tools exist to identify children and families at risk of poor psychosocial outcomes and interventions to improve adjustment and other outcomes. There are several new promising interventions using technology to deliver care and engage special populations.
- More research is needed to facilitate the translation of evidence-based psychosocial assessment and interventions into routine clinical practice.