

Pediatric psycho-oncology care: standards, guidelines, and consensus reports

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Abstract

Objective: The aim of this study was to identify existing guidelines, standards, or consensus-based reports for psychosocial care of children with cancer and their families.

Purpose: Psychosocial standards of care for children with cancer can systematize the approach to care and create a replicable model that can be utilized in pediatric hospitals around the world. Determining gaps in existing standards in pediatric psycho-oncology can guide development of useful evidence-based and consensus-based standards.

Methods: The MEDLINE and PubMed databases were searched by investigators at two major pediatric oncology centers for existing guidelines, consensus-based reports, or standards for psychosocial care of patients with pediatric cancer and their families published in peer-reviewed journals in English between 1980 and 2013.

Results: We located 27 articles about psychosocial care that met inclusion criteria: 5 set forth standards, 19 were guidelines, and 3 were consensus-based reports. None was sufficiently up to date, comprehensive, specific enough, or evidence- or consensus-based to serve as a current standard for psychosocial care for children with cancer and their families.

Conclusion: Despite calls by a number of international pediatric oncology and psycho-oncology professional organizations about the urgency of addressing the psychosocial needs of the child with cancer to reduce suffering, there remains a need for development of a widely acceptable, evidence-based and consensus-based, comprehensive standard of care to guide provision of essential psychosocial services to all patients with pediatric cancer.

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Background

As a result of medical advances over the past 30 years, the survival of patients with pediatric cancer has increased dramatically [1,2]. Research indicates that psychosocial and neurocognitive consequences of cancer and its treatment can have adverse lifelong effects and that psychosocial care is critical to the care of a child with cancer. With the growing demand for accountability and outcome-driven, cost-effective care models, psychosocial clinicians are being challenged to standardize their approaches and evaluate the efficacy of clinical efforts [3]. In 2012, psychosocial researchers in adult oncology formulated standards addressing the psychosocial component of adult cancer care and issued clinical practice guidelines [4]. They have also developed and implemented measurable indicators for the quality of psychosocial care in oncology settings. Currently, efforts are underway to develop standards for the psychosocial care of children with cancer. This necessitates a review of previous work with similar or related goals as well as

recognition of the differences between typical psychosocial care of children and adults.

In most developed countries over the past 30 years, the psychosocial care of children with cancer has typically been more robust and comprehensive than the psychosocial care of adults with cancer. There is more likely to be a common understanding that the entire family unit is adversely affected emotionally, financially, and often geographically by the child’s diagnosis and need for treatment [5]. Care is expected to encompass response to a wide range of developmental, emotional, and communication challenges potentially affecting the child’s well-being. There is recognition that, despite major advances in survival, children do still die of pediatric cancers, and there is a need for psychosocial support and palliative care for those families [6]. Psychosocial care is also essential for survivors, as they have decades of life ahead during which late effects of the pediatric cancer and cancer treatment can have significant adverse impact on quality of life [7]. Because the child is so dependent on one or more parents during and after cancer treatment and the

emotional well-being of the parent has been shown to influence child mood and coping [8], psychosocial care is typically extended to parents and also often to other family members including siblings and, more recently, grandparents [9,10]. Hence, while the methods utilized in development of standards of psychosocial care for adult patients with cancer may be useful to the process of developing pediatric standards, the specific elements are likely to differ significantly.

Several organizations including the International Society of Pediatric Oncology (SIOP) and the Canadian Association of Psychosocial Oncology (CAPO) have published guidelines and consensus statements for segments of the pediatric cancer care continuum, yet none of these reflects fully the current literature in pediatric psychoncology, and none encompasses all aspects of current psychosocial care. Psychosocial care includes assessment and monitoring of the child's cognitive, academic, emotional, spiritual, and practical needs and the family strengths and limitations. It focuses on the provision of interventions across the trajectory of illness with the goal of relieving emotional distress and promoting emotional well-being and optimal functioning during and beyond cancer treatment. For standards of psychosocial care for children with cancer to be widely accepted, they must reflect the existing evidence in well-researched areas and methodically-achieved consensus in areas where research is lacking.

To begin the process of developing pediatric psychosocial standards, we explored published pediatric psychosocial guidelines. This is not a standard review of the current literature in pediatric psycho-oncology. Rather, it is a synthesis of existing attempts to standardize clinical practice in pediatric psycho-oncology in an effort to identify gaps in essential service delivery, interventions, or training and professional standards and updating of related research or consensus attempts in pediatric psycho-oncology. This, then, is the first step toward production of evidence-based and consensus-based, comprehensive, implementable 21st century standards.

Method

Defining standards and guidelines and consensus reports

In this paper, we differentiate between standards, guidelines, and consensus-based reports. Within an oncology setting, Jacobsen and Wagner (2012) define standards as recommendations for 'the organization and delivery of psychosocial care that apply broadly to patients seen in oncology settings' and guidelines as more specific and 'meant to provide information that can be of assistance in making clinical decisions on the basis of specific characteristics of the patient..., the illness... or the clinical circumstance' [4]. Standards, then, are recommendations for

essential services, which should be universally available. Guidelines represent more of a blueprint for high quality care, which can be expected to vary with individual needs and available resources. Jacobsen and Wagner (2012) hold that, 'Like standards, clinical practice guidelines can be developed on the basis of evidence, consensus reports and/or ethical and safety considerations'.

Eligibility criteria and search strategy

A literature search was carried out at two major pediatric oncology hospital centers. At each site, a researcher and a research assistant conducted a review of the published literature from 1980 to 2013 to identify existing guidelines, consensus-based reports, and standards for psychosocial care of children with cancer and their families. Inclusion criteria consisted of (a) articles describing standards, guidelines, or consensus-driven reports in the field of pediatric psycho-oncology with an explicit focus on pediatric or adolescent oncology patients published in a peer review journal in English between 1980 and 2013 or (b) psychosocial cancer care standards that did not exclude pediatric oncology patients. Excluded articles were those that addressed guidelines or standards only for adult patients with cancer, were purely opinion based, or were editorial commentaries.

This search was conducted using Academic Search Premier and PubMed. MEDLINE and PubMed databases were searched using key search terms: [adolescent or pediatric] OR [child or children] AND [oncology or cancer] AND [psychosocial] OR [support] OR [care] OR [standard]. Key articles from reference lists were hand searched using the same eligibility criteria. We conducted a review of this literature, summarized the major focus of each article, and tabulated the content subjects covered to aid future professionals developing standards (Table 1). A researcher at each site reviewed articles meeting eligibility. For final validation, two reviewers independently evaluated the articles for content and type (i.e., whether they were guidelines, standards, or consensus-based recommendations); reconciliation was achieved by telephone discussion.

Results

The combined search yielded 27 articles that provided standards, guidelines, or consensus-based actionable plans relevant to pediatric psychosocial oncology. Five were described as standards, 19 as guidelines, and 3 as consensus-based reports. Key articles are described in the succeeding texts in chronological order within each group category.

Standards

Five published standards were identified for this review, two created by American-based organizations, that is,

Table I. Standards, guidelines, and evidence-based consensus reports on psychosocial support: subjects addressed

Authors/Developers	Title	Report type	Assessment/Screening	Treatment/Interventions	Multidisciplinaryteam/Collaborations	School/School reentry	Remission Relapse	Survivorship	Parents/Marital issues	Siblings	Grandparents	Cultural	Socioeconomic	Community support	End-of-life	Provider training
Arceci, 1996 (ASPH/O) [11]	Comprehensive Pediatric Hematology/Oncology Programs: Standard Requirements for Children and Adolescents with Cancer and Blood Disorders	Standard	x	x	x				x	x						
Thaxter et al., 2002 (SIOP) [12]	International Society of Paediatric Oncology: Standards of Care and Training	Standard		x			x	x	x	x	x		x	x	x	
Institute of Medicine, 2008 [13]	Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs	Standard		x	x									x		
Canadian Association of Psychosocial Oncology, 2010 [14]	Standards of Psychosocial Health Services for Persons with Cancer and their Families	Standard	x	x	x			x							x	x
Kowalczyk et al., 2013 (SIOPE) [15]	Towards Reducing Inequalities: European Standards of Care for Children with Cancer	Standard	x	x	x			x	x				x	x	x	x
Chesler et al., 1993 [16]	Principles of Psychological Programming for Children with Cancer	Guideline			x			x	x			x	x	x	x	
Masera et al., 1993 (SIOP) [17]	SIOP Working Committee on Psychosocial Issues in Pediatric Oncology	Guideline			x	x		x	x	x	x		x	x		x
Masera et al., 1995 (SIOP) [18]	SIOP Working Committee on Psychosocial Issues in Pediatric Oncology: Guidelines for School/Education	Guideline		x			x									
Lauria et al., 1996 (ACS) [19]	Psychosocial Protocol for Childhood Cancer	Guideline	x	x	x	x		x	x	x		x	x	x	x	
Masera et al., 1996 (SIOP) [20]	SIOP Working Committee on Psychosocial Issues in Pediatric Oncology: Guidelines for Care of Long-term Survivors	Guideline	x	x				x						x		
American Academy of Pediatrics, 1997 [21]	Guidelines for the Pediatric Cancer Center and Role of Such Centers in Diagnosis and Treatment	Guideline		x	x			x						x		
Masera et al., 1997 (SIOP) [22]	SIOP Working Committee on Psychosocial Issues in Pediatric Oncology: Guidelines for Communication of the Diagnosis	Guideline			x	x			x					x		
Masera et al., 1998 (SIOP) [23]	Guidelines for a Therapeutic Alliance Between Families and Staff: A Report of the SIOP Working Committee on Psychosocial Issues in Pediatric Oncology	Guideline		x	x			x	x	x	x					
Masera et al., 1999 (SIOP) [24]	Guidelines for Assistance to Terminally Ill Children with Cancer: A Report of the SIOP Working Committee on Psychosocial Issues in Pediatric Oncology	Guideline		x					x	x	x			x	x	
Spinetta et al., 1999 (SIOP) [25]	Guidelines for Assistance to Siblings of Children with Cancer: Report of the SIOP Working Committee on Psychosocial Issues in Pediatric Oncology	Guideline		x			x	x	x	x					x	
Kusch et al., 2000 (University of Bonn) [26]	Structuring Psychosocial Care in Pediatric Oncology	Guideline		x	x				x							
Spinetta et al., 2000 (SIOP) [27]	Guidelines for the Recognition, Prevention, and Remediation of Burnout in Health Care Professionals Participating in the Care of Children with Cancer: Report of the SIOP Working Committee on Psychosocial Issues in Pediatric Oncology	Guideline			x											x
Spinetta et al., 2002 (SIOP) [28]	Refusal, Non-Compliance, and Abandonment of Treatment in Children and Adolescents with Cancer: A Report of the SIOP Working Committee on Psychosocial Issues in Pediatric Oncology	Guideline		x			x		x			x	x	x		

(Continues)

Table 1. (Continued)

Authors/Developers	Title	Report type	Assessment/Screening	Treatment/Interventions	Multidisciplinaryteam/Collaborations	School/School reentry	Remission	Relapse	Survivorship	Parents/Marital issues	Siblings	Grandparents	Cultural	Socioeconomic	Community support	End-of-life	Provider training
Children's Oncology Group, 2004 [29]	Supportive Care of Children with Cancer: Current Therapy and Guidelines from the Children's Oncology Group	Guideline	x	x													x
Children's Oncology Group, 2008 [30]	Long Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers	Guideline	x	x											x		
31Pearce, 2009	Policy and Practice in Teenage and Young Adult Cancer Care in England: Looking to the Future	Guideline	x	x													x
van de Wetering et al., 2011 (Emma Children's Hospital) [32]	Supportive Care of Children with Cancer	Guideline	x	x													
Coccia et al., 2012 (NCCN, LIVESTRONG) [33]	Adolescent and Young Adult Oncology Clinical Practice Guidelines	Guideline	x	x	x			x						x	x	x	
Duff et al., 2012 [34]	Management of Distressing procedures in children and young people: time to adhere to the guidelines	Guideline	x						x								
Edwards, 1998 [35]	Access to Quality Cancer Care: Consensus Statement of the American Federation of Clinical Oncologic Societies	Consensus	x	x				x					x	x		x	
Clarke et al., 2004 (University of York) [36]	Care and Support Needs of Children and Young People with Cancer and Leukaemia and Their Families	Consensus		x					x	x	x					x	
Zebrack et al., 2010 [37] (LIVESTRONG)	Quality Cancer Care for Adolescents and Young Adults: A Position Statement	Consensus	x	x													

the American Society of Pediatric Hematology/Oncology (ASPH/O) and the Institute of Medicine (IOM). The third was developed by CAPO, the fourth by the SIOP, and the final by the European Society of Paediatric Oncology (SIOPE). Neither the IOM nor the CAPO standards are specific to childhood patients cancer, but they were not explicitly designed for adults, so they were included for review. The five standards are discussed briefly in the succeeding texts:

- In 1996, the ASPH/O Health Care Reform and Public Issues Committee created standard requirements for pediatric programs to adequately care for children and adolescents with blood disorders and cancer [11]. These standards included a rationale and recommendations for a comprehensive pediatric hematology/oncology program to be implemented throughout the disease trajectory. The services of psychosocial personnel were explicitly described, although no evidence was available to support the recommendations.
- In 2002, SIOP issued standards for care of children with cancer that proposed ideal care; however, they did not address the necessary specific health care

provider training needs and, most critically, did not provide specific recommendations for their implementation [12].

- In 2008, the US IOM published the 'Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs' [13] that outlined psychosocial needs of patients with cancer of all ages and described consequences of unmet needs. The document includes models for delivery of psychosocial care and recommendations for implementation of standards. However, this report does not specifically focus on care of patients with pediatric cancer and is not as detailed in its recommendations as would be needed to implement standards.
- CAPO began a process of creating standards for all patients with cancer in 1999, and in 2010, they issued their most recent update of the standards, which provide key points for the care of both adult and pediatric patients [14]. However, again, while the recommendations are valuable and extensive, they are not specific for pediatric patients and lack needed detail to be useful in establishing units for psychosocial care.

- In 2013, the SIOPE published standards for the care of children with cancer stating that ‘The implementation of the Standards at a national level, possibly through national cancer plans, would be a vital “next step,” improving the Quality-of-Care for Children with cancer, increasing survival rates and enhancing the Quality-of-Life for childhood cancer survivors’ [15]. The standards broadly cover medical and psychosocial care, hospice care, and rights of the hospitalized child. There is, however, insufficient detail specifically about psychosocial care in pediatric cancer for this standard to fully define essential care in all domains.

Guidelines

Several published guidelines identified ‘ideal’ psychosocial care for a child with cancer [16–34]. None of these documents included all of the information necessary for the complete psychosocial care of a child nor are many explicitly evidence-based or up to date. We included them in our review because they are instructive in defining content that addresses both ideal and essential psychosocial care for children with cancer. Guidelines have been created for specific time points in the disease trajectory of patients with pediatric cancer or for a particular clinical issue. Selected guidelines are discussed here:

- From 1993 to 2002, the SIOP Working Committee published guidelines to address specific clinical challenges faced by pediatric oncology patients, their families, and providers. They provided recommendations for (a) the strategy for psychosocial intervention and structure of socio-economic policies [17], (b) schooling and education during treatment [18], (c) care of long-term survivors [20], (d) communication of the diagnosis [22], (e) maintaining an alliance between family members and the medical team in order to establish open communication [23], (f) helping children with cancer transition from curative to palliative care [24], (g) involving siblings of children with cancer throughout their brothers’ and sisters’ treatment [25], (h) preventing and/or remediate provider burnout [27], and (i) refusal, noncompliance, and abandonment of treatment in children and adolescents with cancer [28]. While each of these guidelines provides important information on a variety of topics, consolidation is needed. Additionally, much has changed in communication about cancer and related social attitudes since the publication of many of these papers, and they do not refer to or include much of the current relevant evidence base.
- In 2000, researchers at the University of Bonn issued a psychosocial care manual that included guidelines oriented to specific phases of the medical treatment

of patients with pediatric cancer [26]. This report discusses management of psychosocial care associated with treatment, specifically focusing on the importance of multidisciplinary teams and the role of psychosocial professionals. More recently, the British Psychological Society issued a set of evidence-based guidelines for management of invasive or distressing procedures for children [34]. This report describes proper procedures and psychosocial care prior to, during, and after procedures, including patient monitoring.

- Recently, the National Comprehensive Cancer Network published guidelines for the support of adolescents and young adults living with cancer and their families [33]. This report provides detailed recommendations in a variety of clinical areas including assessment at diagnosis, evaluation of family dynamics and relationships, psychosocial support throughout the treatment to alleviate distress, referral processes to specialized professionals, and the importance of multidisciplinary collaboration. Although more complete than most other published guidelines, these are embedded within medical and treatment-based recommendations. This guideline is entirely evidence-based and can serve as an important model to inform development of psychosocial standards. However, it refers only to older pediatric and young adult patients and, thus, is insufficiently comprehensive.

Consensus statements

In the consensus paper category, we included observations reported by groups or committees of experts in the field of psycho-oncology [35–37]. Such reports are needed, as there remain broad categories of the field that have not been systematically studied, especially studies of professional training, practice, and support for professionals.

- In 1998, the American Federation of Clinical Oncologic Societies issued a consensus statement on providing access to quality cancer care [35]. This statement was focused on medical treatment and intervention but offered recommendations for support groups, counseling services, and professional psychotherapeutic services, while highlighting, but not detailing, the need for increased access to psychosocial services. This document also did not specifically focus on the pediatric population.
- In 2004, the National Comprehensive Cancer Network issued an evidence-based consensus statement regarding the care and support needs of children and young people with leukemia and their families. This document emphasized the need for provision of age-appropriate information at all time points in the disease trajectory, as well as a need to

provide services to all family members through significant or transition points [36]. While this report defined broad areas of unmet need in psychosocial care of patients with pediatric cancer, it did not provide specific recommendations for meeting those needs.

- More recently, the LIVESTRONG Young Adult Alliance offered recommendations for quality cancer care for adolescents and young adults [37]. The position statement identified four critical elements of quality care, including access to health care professionals who possess knowledge of the psychosocial needs specific to this population. The other three critical elements were not only focused on treatment and medical intervention but also discussed possible psychosocial approaches and measurable outcomes. The limitation of this document is that it concerns only a subset of the pediatric oncology population and lacks specificity about the needed services.

Smaller groups of experts have published reports that explored current trends in psychosocial practices and provided an overview of the gaps in psychosocial care for children with cancer and their families, with recommendations on how to address these issues [38–46]. While all of these documents are valuable in defining unmet needs for specific aspects of psychosocial care of patients with pediatric cancer, they are not sufficiently comprehensive in their recommendations to serve as standards.

Discussion

Despite calls by the IOM, American Academy of Pediatrics, SIOP, and other professional organizations about the urgency of addressing the psychosocial needs of the child with cancer in order to reduce suffering, we are lacking a widely accepted, up-to-date, evidence-based and consensus-based, comprehensive standard to guide provision of essential psychosocial services to all patients with pediatric cancer. Standards are the first order of business, providing a guiding structure for the development of new pediatric psycho-oncology services and a checklist for the provision of essential care in all established programs. Guidelines typically follow, highlighting ways to provide optimal care, which is often not fully achievable in less well-resourced programs but providing a shining example of ultimate, ideal care goals. The relationship between research evidence and the creation of standards and guidelines is bidirectional; evidence forms the basis for strong recommendations. Strong evidence, such as that concerning the need for neurocognitive assessment and academic remediation in response to the late effects of treatment for childhood brain tumors, allows for strong recommendations in this

area. In turn, we suggest that when a review of the standards reveals an area where there is an absence of high-quality research evidence, it is there that consensus among experts is needed for the development of current standards. These areas are also thus identified as good targets for future research studies. Resulting data can then support the possibility of creating even stronger, more firmly evidence-based recommendations in future standards and guidelines.

Conclusion

This brief review of the notable past efforts to define psychosocial care for children with cancer not only provides an overview but also underscores the reasons why new standards are needed. While there is much value in these documents, significant gaps remain in the literature on the problems and burdens experienced by patients with pediatric oncology and their families and on methods for screening, assessment, intervention, and support in pediatric psycho-oncology. Despite the past three decades of research, evidence in pediatric psycho-oncology is very uneven, and there are many areas where there are few, if any, studies on important questions. Examples of knowledge gaps in pediatric psycho-oncology include the lack of definitive research on the efficacy of many supportive interventions, optimal assessment intervals, impact of low socioeconomic or minority status on burden of care and psychosocial outcomes, school reentry and academic functioning, end-of-life care, and the essential elements of provider training, supervision, and burnout prevention. As a result, in addition to assessing the quality of current research in areas where studies exist, utilizing accepted methods such as the Appraisal of Guidelines for Research and Evaluation instrument (AGREE) [47], we must continue to also rely on systematic ways of reaching consensus in areas lacking an evidence base.

Currently, the Psychosocial Standards of Care Project for Childhood Cancer, an international multidisciplinary group of professionals supported by the Mattie Miracle Cancer Foundation and co-led by Drs. Anne Kazak, Mary Jo Kupst, Robert Noll, Andrea Farkas Patenaude, and Lori Wiener, is working to establish standards for the psychosocial care of patients with pediatric cancer. The group is reviewing existing literature with the aim of incorporating evidence about the value of services and interventions provided to children with cancer. It is also reviewing consensus reports about services, training, and professional support in understudied areas. Treatments with broadly accepted value will be included in the standards, along with a call for additional research on less well-proven interventions. This group is committed to creating and disseminating a 21st century blueprint to support universally available psychosocial services for children with cancer and their families.

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