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Pediatric Psycho-oncology Care: Standards, Guidelines and Consensus Reports

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Abstract

Objective—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- 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 pediatric cancer patients 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 guidelines and 3 were consensus-based reports. None were sufficiently up-to-date, significantly evidence-based, comprehensive and specific enough 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 in order to reduce suffering, there remains a need for development of a widely acceptable, evidence- and consensus-based, comprehensive standard of care to guide provision of essential psychosocial services to all pediatric cancer patients.

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Background

As a result of medical advances over the past 30 years, the survival of pediatric cancer patients 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.

Several organizations including the International Society of Paediatric Oncology (SIOP) and the Canadian Association of Psychosocial Oncology (CAPO) have guidelines and consensus statements for segments of the pediatric cancer care continuum, yet none of these reflect fully the current literature in pediatric psycho-oncology and none encompasses all aspects of current psychosocial care. 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-developed 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 hopes of identifying the gaps which must be filled to produce evidence-based, 21st century standards. In this paper, we differentiate between standards, guidelines, and consensus-based reports, with standards representing the minimal but essential aspects of care that should be available to all pediatric oncology patients and family members. Guidelines represent what is advisable or ideal, and may vary due to individual needs and available resources. Consensus reports may come from committee meetings or independent groups of experts and include recommendations about particular aspects of psychosocial care. Review of this literature can guide development of evidence-based, implementable standards that incorporate expert consensus.

Method

Eligibility criteria and search strategy

A literature search was carried out at 2 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 (1) 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 (2) psychosocial cancer care standards which did not exclude pediatric oncology patients.

Excluded articles were those that addressed guidelines or standards only for adult cancer patients, 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 topics to aid future professionals developing standards. (see 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 below in chronological order within each group category.

Standards

Five published standards were identified for this review, two created by American-based organizations, i.e. the American Society of Pediatric Hematology/Oncology (ASPH/O) and the Institute of Medicine (IOM). The third was developed by Canadian Association of Pediatric Oncology (CAPO), the fourth by the International Society of Pediatric Oncology (SIOP), and the final by the European Society of Paediatric Oncology (SIOPE). Neither the IOM nor the CAPO standards are specific to childhood cancer patients, but they were not explicitly designed for adults, so they were included for review. The 5 standards are discussed briefly below:

- 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 [5]. 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 though 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 healthcare provider training needs and, most critically, did not provide specific recommendations for their implementation [6].
- In 2008, the U.S. Institute of Medicine published “Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs” [7] which outlined psychosocial needs of cancer patients 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 pediatric cancer patients and is not as detailed in its recommendations as would be needed to implement standards.

- CAPO began a process of creating standards for all cancer patients 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 [8]. 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 European Society of Paediatric Oncology 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” [9]. The Standards broadly cover medical and psychosocial care, hospice care and rights of the hospitalized child. There is, however, not sufficient 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 [10-28]. 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 pediatric cancer patients 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 1) the strategy for psychosocial intervention and structure of socio-economic policies [11], 2) schooling and education during treatment [12], 3) care of long-term survivors [14], 4) communication of the diagnosis [16], 5) maintaining an alliance between family members and the medical team in order to establish open communication [17], 6) helping children with cancer transition from curative to palliative care [18], 7) involving siblings of children with cancer throughout their brothers’ and sisters’ treatment [19], 8) preventing and/or remediating provider burnout [21], and 9) refusal, non-compliance, and abandonment of treatment in children and adolescents with cancer [22]. 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 pediatric cancer patients [20]. 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 [28]. This report describes proper procedures and psychosocial care prior to, during, and after procedures, including patient monitoring.
- More recently, the National Comprehensive Cancer Network published guidelines for the support of adolescents and young adults living with cancer and their families [27]. This report provides detailed recommendations in a variety of clinical areas including assessment at diagnosis, evaluation of family dynamics and relationships, psychosocial support throughout treatment to alleviate distress, referral processes to specialized professionals, and the importance of multi-disciplinary collaboration. Though 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 [29-31]. 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 [29]. 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 [30]. While this report defined broad areas of unmet need in psychosocial care of pediatric cancer patients, 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 [31]. 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 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 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 [32-40]. While all of these documents are valuable in defining unmet needs for specific aspects of psychosocial care of pediatric cancer patients, they are not sufficiently comprehensive in their recommendations to serve as standards.

Conclusion

Evidence-based clinical practice is an approach to decision-making in which the clinician uses the best evidence available, in consultation with the patient, to decide upon the option, which suits that patient best [41]. Despite calls by the IOM, AAP, SIOP and other professional organizations about the urgency of addressing the psychosocial needs of the child with cancer in order to reduce suffering, no widely accepted, sufficiently up-to-date, significantly evidence-based, comprehensive and specific standard of care is available to guide provision of essential psychosocial services to all pediatric cancer patients. This brief review of the notable past efforts to define psychosocial care for children with cancer provides an overview but also underscores the reasons why new standards are needed. While there is much of value in these documents, significant gaps remain and greater specificity is needed about the steps required to meet the essential psychosocial needs of children with cancer and their family members. Despite the past 3 decades of research, we still do not have a complete body of research in all relevant areas of psychosocial care or research on the training and support needs of psychosocial providers, so we must continue to rely also on systematic ways of reaching consensus in areas lacking an evidence base. Currently, the Psychosocial Standards of Care Project for Childhood Cancer, an international, multi-disciplinary group of professionals supported by the Mattie Miracle Cancer Foundation, is working to establish standards for the psychosocial care of pediatric cancer patients. 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 these topics. This group is committed to creating and disseminating a 21st century, widely applicable blueprint to support universally available psychosocial services.

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Table 1
Standards, Guidelines, and Evidence-Based Consensus Reports on Psychosocial Support: Subjects Addressed

Authors/Developers	Title	Report Type	Assessment/Screening	Treatment/Interventions	Multidisciplinary Team/ Collaborations	School/School re-entry	Remission	Relapse	Survivorship	Parents/ Marital Issues	Siblings	Grandparents	Cultural	Socioeconomic	Community Support	End -of-life	Provider Training
7 Arceci, 1996 (ASPHO)	Comprehensive Pediatric Oncology/ Oncology Programs: Standard Requirements for Children and Adolescents with Cancer and Blood Disorders	Standard		x	x	x				x	x						
8 Hawer et al., 2002 (SIOP)	International Society of Paediatric Oncology: Standards of Care and Training	Standard		x		x		x	x	x	x			x	x	x	
9 Institute of Medicine, 2008	Cancer Care for the Whole Person: Meeting Psychosocial Health Needs	Standard		x	x										x		
10 Canadian Association of Psychosocial Oncology, 2010	Standards of Psychosocial Health Services for Persons with Cancer and their Families	Standard	x	x	x				x							x	x
11 Kowalczyk et al., 2013 (SIOPE)	Towards Reducing Inequalities: European Standards of Care for Children with Cancer	Standard		x	x	x			x	x				x	x	x	x
12 Chesler et al., 1993	Principles of Psychological Programming for Children with Cancer	Guideline			x				x	x			x	x	x	x	
13 Massem et al., 1993 (SIOP)	SIOP Working Committee on Psychosocial Issues in Pediatric Oncology	Guideline			x	x			x	x	x			x	x		x

Authors/Developers	Title	Report Type	Assessment/Screening	Treatment/Interventions	Multidisciplinary Team/Collaborations	School/School re-entry	Remission	Relapse	Survivorship	Parents/ Marital Issues	Siblings	Grandparents	Cultural	Socioeconomic	Community Support	End-of-life	Provider Training
14 Masera et al. 1995 (SIOP)	SIOP Working Committee on Psychosocial Issues in Pediatric Oncology: Guidelines for Social Education	Guideline		x		x	x										Wiener et al.
15 Lamm et al. 1996 (ACS)	Psychosocial Protocol for Childhood Cancer	Guideline		x	x	x	x		x	x	x		x	x		x	
16 Masera et al. 1996 (SIOP)	SIOP Working Committee on Psychosocial Issues in Pediatric Oncology: Guidelines for Care of Long-term Survivors	Guideline		x	x				x						x		
17 American Academy of Pediatrics, 1997	Guidelines for the Pediatric Cancer Center and Role of Such Centers in Diagnosis and Treatment	Guideline		x	x				x						x		
18 Masera et al. 1997 (SIOP)	SIOP Working Committee on Psychosocial Issues in Pediatric Oncology: Guidelines for Communication of the Diagnosis	Guideline			x	x				x					x		
19 Masera et al. 1998 (SIOP)	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	x					
20 Masera et al. 1999 (SIOP)	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	
21 Spinetta et al. 1999 (SIOP)	Guidelines for Assistance to Siblings of Children	Guideline		x			x	x		x	x					x	

Authors/Developers	Title	Report Type	Assessment/Screening	Treatment/Interventions	Multidisciplinary Team/Collaborations	School/School re-entry	Remission	Relapse	Survivorship	Parents/ Marital Issues	Siblings	Grandparents	Cultural	Socioeconomic	Community Support	End-of-life	Provider Training
	with Cancer: Report of the SIOOP Working Group; Report of the SIOOP Working Committee on Psychosocial Issues in Pediatric Oncology																Wiener et al.
22 Kusch et al., 2000 (University of Bonn)	Structuring Psychosocial Care in Pediatric Oncology	Guideline		×	×					×							
23 Spinetta et al., 2000 (SIOOP)	Guidelines for the Recognition, Prevention, and Remediation of Burnout in Health Care Professionals Participating in the Care of Children with Cancer: Report of the SIOOP Working Committee on Psychosocial Issues in Pediatric Oncology	Guideline			×								×				×
24 Spinetta et al., 2002 (SIOOP)	Refusal, Non-compliance, and Abandonment of Treatment in Children and Adolescents with Cancer: A Report of the SIOOP Working Committee on Psychosocial Issues in Pediatric Oncology	Guideline		×			×			×			×	×	×		
25 Children's Oncology Group, 2004	Supportive Care of Children with Cancer: Current Therapy and Guidelines from the Children's Oncology Group	Guideline		×	×												×
26 Children's Oncology Group, 2008	Long Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers	Guideline	×	×										×			
27 Pearce, 2009	Policy and Practice in Teenage and Young Adult	Guideline		×	×												×

Authors/Developers	Title	Report Type	Assessment/Screening	Treatment/Interventions	Multidisciplinary Team/Collaborations	School/School re-entry	Remission	Relapse	Survivorship	Parents/ Marital Issues	Siblings	Grandparents	Cultural	Socioeconomic	Community Support	End-of-life	Provider Training	
	Cancer Care in England: Looking to the Future Cancer Care in England: Looking to the Future Cancer Care in England: Looking to the Future																	Wiener et al.
28. van de Weering et al, 2011 (Emma Children's Hospital)	Supportive Care for Children with Cancer	Guideline		x	x													
29. Coccia et al, 2012 (NCCN, LIVESTRONG)	Adolescent and Young Adult Oncology Clinical Practice Guidelines	Guideline	x	x	x				x					x	x	x		
30. Duff et al, 2012	Management of Distressing procedures in children and young people: time to adhere to the guidelines	Guideline		x						x								
31. Edwards, 1998	Access to Quality Cancer Care: Consensus Statement of the American Federation of Clinical Oncologic Societies	Consensus		x	x				x				x	x		x		
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33. Zelnack et al, 2010 (LIVESTRONG)	Quality Cancer Care for Adolescents and Young Adults: A Position Statement	Consensus		x	x													