

Psychosocial standards of care for children with cancer and their families: A national survey of pediatric oncology social workers

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ABSTRACT

In 2015, an interdisciplinary group of psychosocial experts developed The Standards of Psychosocial Care for Children with Cancer and Their Families. This paper presents data from a national survey of pediatric oncology social workers and their experiences in delivering psychosocial care to children and families. In total, 107 social workers from 81 cancer institutions participated in a 25-item online survey that mirrored the 15 Standards for Psychosocial Care. Both closed and open-ended questions were included.

Social work participants reported that psychosocial support is being provided at most cancer centers surveyed, primarily by social workers and child life specialists, addressing adaptation to the cancer diagnosis, treatment, and transitions into survivorship or end-of-life care and bereavement. While social workers reported offering comprehensive services throughout the cancer trajectory, many of the 2015 Standards are not being *systematically* implemented. Areas for improvement include funding for psychosocial support staff and programs, incorporation of standardized assessment measures, assessment for financial burden throughout treatment and beyond, consistent access to psychology and psychiatry, integrated care for parents and siblings, and more inclusion of palliative care services from time of diagnosis.

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Introduction

The diagnosis and treatment of childhood cancer generates considerable psychosocial distress for the child and family (Boman, Lindahl, & Björk, 2003; Wijnberg-Williams, Kamps, Klip, & Hoekstra-Weebers, 2006). Even with increasing survival rates, childhood cancer requires prolonged and complicated treatments that can impact quality of life (Long & Marsland, 2011; Wiener et al., 2016). Although most families adjust over time (Kazak et al., 2006; Price, Kassam-Adams, Alderfer,

Christofferson, & Kazak, 2016), a significant number of children and families exhibit long-term psychosocial difficulties (Alderfer, Kazak, Canaan, & Annunziato, 2005; Boman et al., 2003; Kupst & Patenaude, 2015; Wijnberg-Williams et al., 2006). Early and ongoing identification of psychosocial needs and implementation of child and family interventions may reduce immediate and long-term adverse psychosocial effects (Abrams, Muriel, & Wiener, 2015).

Following the loss of their only child to cancer, Vicki and Peter Brown created the Mattie Miracle Cancer Foundation (MMCF). One of their goals was to standardize the delivery of psychosocial care to all children with cancer and their family members. This goal led to the creation of the Psychosocial Standards of Care Project for Childhood Cancer (PSCPCC) in 2012. The PSCPCC engaged over 80 multidisciplinary professionals and parent advocates in a rigorous methodology over a 3-year period that resulted in the development of 15 evidence-based Standards (Wiener, Kazak, Noll, Patenaude, & Kupst, 2015a). The Standards, published in December of 2015, cover psychosocial care throughout the cancer trajectory, including survivorship and bereavement, and have been endorsed and/supported by 15 key professional groups, including the Association of Pediatric Oncology Social Workers (APOSW).

This first national study to investigate trends in the provision of pediatric psychosocial care following the publication of the Standards found social workers and child life specialists provide 90% of psychosocial care to children and families in oncology settings (Scialla et al., 2017). The data showed that social workers and child life specialists form the backbone of psychosocial care with social workers being the front-line providers. The study, which included psychosocial leaders from pediatric oncology institutions ($n = 144$), also identified challenges in organizational culture including staffing limitations due to reimbursement and time constraints.

The present study aimed to explore, from pediatric oncology social workers' perspectives, staffing ratios and institutional practices, current social work practices in psychosocial supportive care, and barriers to implementing the Standards in their respective work settings.

Method

During the 40th Annual Psychosocial Care for Children with Cancer and their Families. The presentation included the history and mission of the MMCF and the rigorous multiyear process used to create the 15 evidence-based Standards for pediatric psychosocial care (Wiener et al., 2015a). APOSW members were asked to consider participating in an upcoming online survey about their institution's provision of psychosocial care services and about how closely those services relate to the Standards. One week following the presentation, members of the APOSW Listserv ($n = 269$) received an email invitation to respond to an online survey. Appendix A includes a list of the survey questions.

Social workers were provided a link to the Standards and were encouraged to familiarize themselves with them (Wiener et al., 2015a), thus equipping themselves with a framework with which to report on the practices of their individual institutions. [Appendix B](#) displays the Standards of Pediatric Psychosocial Care for Children with Cancer and their Families.

Two weeks later, APOSW Listserv members received a second email as a reminder to complete the survey. The survey remained open for 4 weeks. Participants were instructed to only have one response per institution. The study was approved by the University of Texas at Austin's Institutional Review Board.

Measurement

A 25-item survey was developed by the authors. The survey questions mirrored the 15 Standards for Psychosocial Care (Wiener et al., 2015a) and included both closed and open-ended questions. Survey questions focused on institutional staffing levels, utilization of standardized assessment tools, staffing credentials and training, as well as targeted questions based on the 15 Standards to discover the type and frequency of support services provided for pediatric oncology patients and their family members. Open-ended questions allowed participants to describe features of their psychosocial programs, along with program strengths and perceived barriers to provision of psychosocial care. The survey took approximately 20 minutes to complete and was carried out through Survey Monkey, an online survey platform.

Statistical analysis

Univariate distributions were calculated for responses to each item on the survey. Descriptive results from the study were summarized based on number and percentage of responses. Bivariate cross-tabulations were calculated to investigate distributions of staffing and services offered based on institutional size. Analysis of descriptive results such as institutional region, number of patients treated each year, and staffing numbers were calculated using IBM SPSS, Version 23 (IBM, 2013). A review of the study's open-ended responses provided opportunities for discovery of institutional differences and barriers. One author reviewed the responses to open-ended questions to capture institutional, socioeconomic, and cultural barriers to care. The same author calculated the frequencies of participants' reported barriers by Standard and drew from participants' direct quotes to highlight barriers.

Results

Responses to the survey came from 107 pediatric oncology social workers. The survey instructions asked respondents to limit their responses to just one response

per institution. When duplicate responses occurred, only the first response from each institution was included, thus resulting in 22 excluded responses. Survey responses from institutions that had satellite sites or unique programs that were distinct were not excluded since these sites included different numbers of patients, clinical staff, and availability of support services. Additionally, four participants who provided no institutional name were excluded from the study to prevent potential duplication of responses. The final study sample of social work participants represented 81 institutions. Members responded from 30 states and the District of Columbia, with the highest number of responses coming from members in California and the northeast region of the United States.

Participants reported that psychosocial support staff included social workers, child life specialists, psychologists, and psychiatrists. These providers assist children, siblings, and parents with their adaptation to the cancer diagnosis, treatment, and transitions into survivorship or bereavement. Approximately half ($n = 41$, 50.6%) of the social work participants reported that their institutions treated more than 90 new pediatric oncology patients each year. All but one of the institutions reported offering psychosocial services to children and their families. Larger institutions typically had more staff (including social workers) available to meet family needs. The number of social workers per institution included the following: one ($n = 29$, 35.8%), two ($n = 23$, 28.4%), three ($n = 11$, 13.6%), four ($n = 8$, 9.9%), and five or more ($n = 10$, 12.3%). A majority of institutions either had no or only one psychologist ($n = 33$, 40.7%, $n = 31$, 38.3% respectively), as well as no or only one psychologist that provided neuropsychological testing ($n = 33$, 40.7%; $n = 31$, 38.3%, respectively). While a few institutions had five or more psychologists ($n = 3$, 3.7%) on staff, no institution had more than three psychologists that provided neuropsychological testing on staff. Access to psychiatrists was most limited with 49.4% ($n = 40$) having no psychiatrists on staff and 22.2% ($n = 18$) having psychiatrists available “sometimes.” [Table 1](#) displays a descriptive overview of the infrastructure of psychosocial care, availability of staffing, and the distribution of providers and services by institutional size. Participants’ responses to the survey items appear in [Table 2](#). Direct quotes from participants about the barriers they experienced in accessing staff and in implementing the Standards are presented in [Table 3](#).

Assessment of psychosocial needs (Standard 1)

Institutions employed different methods for assessing psychosocial needs of their patients and families. Not all participants opted to elaborate on their institution’s assessment process, but of the 58 institutions that did, 11 (18.9%) reported that their institutions utilized a validated assessment tool while 19 (32.8%) used an in-house tool and 25 (43.1%) used no tool at all. Three (5.2%) of the institutions were in the planning phase for implementing a psychosocial screening process. The Psychosocial Assessment Tool (PAT)

Table 1. Infrastructure of psychosocial care and availability of behavioral health providers by number of pediatric oncology patients treated annually.

Item	N = 81 Number (%)	Less than 30 Number (%)	Number of patients treated annually			
			30–60 Number (%)	61–90 Number (%)	91–120 Number (%)	More than 120 Number (%)
Number of childhood cancer patients treated annually by institution ^a						
<30	11 (13.6)	–	–	–	–	–
30–60	13 (16.0)					
61–90	15 (18.5)	–	–	–	–	–
91–120	11 (13.6)	–	–	–	–	–
>120	30 (37.0)	–	–	–	–	–
Number of social workers by institution designated for pediatric patients and families						
None	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
One	29 (35.8)	11 (38.0)	6 (20.7)	6 (20.7)	3 (10.3)	3 (10.3)
Two	23 (28.4)	0 (0.0)	6 (26.2)	9 (39.1)	3 (13.0)	5 (21.7)
Three	11 (13.6)	0 (0.0)	1 (9.0)	0 (0)	3 (27.3)	7 (63.7)
Four	8 (9.9)	0 (0.0)	0 (0.0)	1 (12.5)	2 (25.0)	5 (62.5)
Five or more	10 (12.3)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	10 (100.0)
Number of psychologists by institution that provide psychosocial services to pediatric cancer patients						
None	33 (40.7)	7 (21.2)	5 (15.2)	8 (24.2)	5 (15.2)	8 (24.2)
One	31 (38.3)	3 (9.7)	7 (22.6)	4 (12.9)	5 (16.1)	12 (38.7)
Two	13 (16.0)	2 (15.4)	1 (7.7)	3 (23.0)	1 (7.7)	6 (46.2)
Three	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Four	1 (1.2)	0 (0.0)	1 (100.0)	0 (0.0)	0 (0.0)	0 (0.0)
Five or more	3 (3.7)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	3 (100.0)
Number of psychologists that provide neuropsychological testing						
None	33 (40.7)	9 (27.3)	9 (27.3)	5 (15.2)	3 (9.0)	7 (21.2)
One	31 (38.3)	1 (3.2)	3 (9.7)	7 (22.6)	6 (19.3)	14 (45.2)
Two	13 (16.0)	1 (7.7)	1 (7.7)	2 (15.4)	2 (15.4)	7 (53.8)
Three	4 (4.9)	0 (0.0)	0 (0.0)	2 (50.0)	0 (0.0)	2 (50.0)
Four	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Five or more	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Access to psychiatrists ^a						
None	40 (49.4)	5 (12.5)	6 (15.0)	7 (17.5)	6 (15.0)	16 (40.0)
Sometimes	18 (22.2)	3 (16.7)	1 (5.6)	5 (27.7)	3 (16.7)	6 (33.3)
Usually	15 (18.5)	3 (20.0)	3 (20.0)	4 (26.7)	2 (13.3)	3 (20.0)
Always	7 (8.6)	0 (0.0)	2 (28.6)	0 (0.0)	0 (0.0)	5 (71.4)
Access to on-site mental healthcare for parents ^a						
Neither psychiatrist or psychologist	28 (34.6)	6 (21.4)	4 (14.3)	7 (25.0)	2 (7.2)	9 (32.1)
Psychiatrist only	2 (2.5)	0 (0.0)	0 (0.0)	0 (0.0)	1 (50.0)	1 (50.0)
Psychologist only	26 (32.1)	1 (3.8)	3 (11.5)	4 (15.4)	6 (23.1)	12 (46.2)
Both psychiatry and psychology	21 (25.9)	3 (14.3)	5 (23.8)	3 (14.2)	2 (9.5)	8 (38.2)
Utilization of standardized measure to assess parent/caregiver mental health concerns ^a						
Yes	6 (7.4)	0 (0.0)	0 (0.0)	3 (50.0)	1 (16.7)	2 (33.3)
No	71 (87.7)	10 (14.1)	12 (16.9)	10 (14.1)	11 (15.5)	28 (39.4)

(Continued)

Table 1. (Continued).

Item	N = 81 Number (%)	Less than 30 Number (%)	Number of patients treated annually			
			30–60 Number (%)	61–90 Number (%)	91–120 Number (%)	More than 120 Number (%)
Access to bereavement services ^a						
All services provided on-site	5 (6.2)	0 (0.0)	1 (20.0)	2 (40.0)	2 (40.0)	0 (0.0)
Some on-site and the remainder referred to the community	36 (44.4)	6 (16.7)	4 (11.1)	6 (16.7)	5 (13.8)	15 (41.7)
All referrals made to the community	26 (32.1)	2 (7.7)	7 (26.9)	5 (19.2)	2 (7.7)	10 (38.5)
No bereavement services offered	4 (4.9)	0 (0.0)	0 (0.0)	0 (0.0)	1 (25.0)	3 (75.0)

^aSome data were not available for all questions. Percentages are based on the available data.

(Kazak, Schneider, DiDonato, & Pai, 2015; Kazak et al., *in press*) was the most commonly utilized standardized PAT followed by the National Comprehensive Cancer Network's Distress Thermometer (Holland & Bultz, 2007).

Monitoring for neuropsychological outcomes in children with brain tumors or neuropsychological deficits resulting from treatment (Standard 2)

Neuropsychological monitoring was reported to be provided at the majority of the institutions during treatment ($n = 69$, 85.2%) and after treatment ($n = 70$, 86.4%). The most common approach to neuropsychological testing occurred when problems develop during treatment ($n = 53$, 65.4%) or after the completion of treatment ($n = 50$, 61.7%).

Screening for psychosocial functioning for long-term survivors (Standard 3)

Of the 43 social workers that provided additional feedback on their institutions' management of childhood cancer survival, 23 (28.4%) shared that their institution offered survivorship clinics that utilize a multidisciplinary approach to evaluate and treat the spectrum of late effects. This included routine monitoring for educational and vocational progress ($n = 39$, 48.1%), distress, depression, and anxiety ($n = 38$, 46.9%) and for risky health behaviors such as drinking and smoking ($n = 37$, 45.7%).

Access to psychosocial support throughout the treatment trajectory (Standard 4)

Participants reported that the majority ($n = 76$, 93.9%) of institutions "always" or "usually" provided children with access to psychosocial support interventions throughout the cancer trajectory ($n = 54$, 66.7%, and $n = 22$, 27.2%, respectively).

Table 2. Pediatric oncology psychosocial support survey results.

Standard item	Itemized results(N = 81)
Approximate number of childhood cancer patients treated at your site annually? ^a	<30 = 11(13.6%) 30–60 = 13(16.0%) 61–90 = 15 (18.5%) 91–120 = 11(13.6%) >120 = 30 (37.0%)
How many social workers at your site provide services to pediatric patients?	None: 0 (0%) One: 29(35.8%) Two: 23(28.4%) Three: 11 (13.6%) Four: 8 (9.9%) Five or more: 10 (12.3%)
How many psychologists at your site provide psychosocial services to pediatric cancer patients?	None: 33 (40.7%) One: 31 (38.3%) Two: 13 (16.0%) Three: 0 (0%) Four: 1 (1.2%) Five or more: 3 (3.7%)
How many psychologists at your site provide neuropsychological testing to pediatric cancer patients?	None: 33(40.7%) One: 31 (38.3%) Two: 13 (16.0%) Three: 4 (4.9%) Four: 0 (0%) Five or more: 0 (0%)
Is a process in place for youth with cancer and their families to receive assessments of their psychosocial healthcare needs?	None: 6 (7.4%) At least once: 53 (65.4%) Regularly scheduled:22 (27.2%)
When do patients with brain tumors (and others at high risk for neuropsychological deficits as a result of their cancer treatment) receive for monitoring neurological-psychological deficits? ^a	<i>During treatment:</i> Never: 8 (9.9%) Clinically indicated or symptoms displayed: 53 (65.4%) Routinely: 16 (19.8%) <i>After treatment:</i> Never: 8 (9.9%) Clinically indicated or symptoms displayed: 50 (61.7%) Routinely 20 (24.7%)
How frequently do long-term survivors of child and adolescent cancers receive psychosocial screenings for adverse education and/or vocational progress and relationship difficulties? ^a	Never: 8 (9.9%) When clinically indicated or if symptoms arise: 31 (38.3%) Routinely: 39 (48.1%)
How frequently do long-term survivors of child and adolescent cancers receive psychosocial screenings for distress, depression, and anxiety? ^a	Never: 6 (7.4%) When clinically indicated or with symptoms: 34 (42.0%) Routinely: 38 (46.9%)
How frequently do long-term survivors of child and adolescent cancers receive psychosocial screenings for risky health behaviors? ^a	Never: 7 (8.6%) When clinically indicated or if symptoms arise: 34 (42.0%) Routinely: 37 (45.7%)
Do youth have access for psychosocial support interventions throughout cancer trajectory?	None: 0(0%) Sometimes: 5 (6.2%) Usually: 22 (27.2%) Always: 54 (66.7%)
Availability of psychiatrists? ^a	None: 40 (49.4%)

(Continued)

Table 2. (Continued).

Standard item	Itemized results(N = 81)
	Sometimes: 18 (22.2%) Usually: 15 (18.5%) Always: 7(8.6%)
Does your institution provide on-site mental health care for parents? ^a	Neither psychiatric or psychological services: 28 (34.6%) Both psychiatric and psychological services: 21 (25.9%) Psychiatric only: 2 (2.5%) Psychological only:26 (32.1%)
How often is the risk for financial hardship assessed for pediatric oncology families? ^a	<i>At time of diagnosis:</i> Never: 2 (2.5%) At least once: 27 (33.3%) Systematically: 47 (58.0%) <i>Throughout treatment:</i> Never: 4 (4.9%) At least once: 32(39.5%) Systematically: 39 (48.1%) <i>During survivorship:</i> Never: 19 (23.5%) At least once: 33 (40.7%) Systematically: 21 (25.9%) <i>Bereavement:</i> Never: 20 (24.7%) At least once: 41 (50.6%) Systematically: 12 (14.8%)
How often are parents of children with cancer assessed for their mental health needs? ^a	<i>At time of diagnosis:</i> Never: 0 (0%) If clinically indicated or symptoms arise: 27 (33.3%) Systematically: 49 (60.5%) <i>During treatment:</i> Never: 0 (0%) If clinically indicated or symptoms arise: 53 (65.4%) Systematically 24 (29.6%) <i>Survivorship:</i> Never: 9 (11.1%) If clinically indicated or symptoms arise: 43 (53.1%) Systematically: 22 (27.2%) <i>Bereavement:</i> Never: 13 (16.0%) If clinically indicated or symptoms arise: 51 (63.0%) Systematically: 10 (12.3%)
Are there standardized measures used to assess parents/ caregivers' mental health concerns? ^a	Yes: 5 (6.2%) No: 71 (87.7%)
How often do youth with cancer and their family members receive psychoeducation, information, and anticipatory guidance? ^a	<i>Disease and treatment:</i> Never: 1 (1.2%) If clinically indicated or symptoms arise: 21 (25.9%) Regularly: 55 (67.9%) <i>Relating to hospitalization:</i> Never: 1 (1.2%)

(Continued)

Table 2. (Continued).

Standard item	Itemized results(N = 81)
	If clinically indicated or symptoms arise: 32 (39.5%) Regularly: 44 (54.3%) <i>Relating to psychosocial adaptation:</i> Never: 1 (1.2%) If clinically indicated or symptoms arise: 33 (40.7%) Regularly: 43 (53.1%) <i>Relating to invasive procedures:</i> Never: 1 (1.2%) When requested: 16 (19.8%) Always: 59 (72.8%)
What opportunities for social interaction with others their age are provided to children and adolescents during treatment and/or survivorship? ^a	None: 1 (1.2%) Sometimes: 47 (58.0%) Always: 29 (35.8%)
How often are siblings of children with cancer provided with psychosocial support and interventions? ^a	Never: 2 (2.5%) Sometimes: 51 (63.0%) Always: 24 (29.6%)
How often are the following groups provided with support for the reentry of a childhood cancer patient into school? ^a	<i>Support for school reentry offered to children and parents:</i> Never: 3 (3.7%) Sometimes: 28 (34.6%) Always: 44 (54.3%) <i>School reentry support offered to schools and teachers:</i> Never: 4 (4.9%) Sometimes: 47 (58.0%) Always: 23 (28.4%)
How is adherence assessed and monitored throughout treatment? ^a	None: 6 (7.4%) If concern is identified: 36 (44.4%) Regularly: 31 (38.3%) Never: 9 (11.1%) Sometimes: 59 (72.8%) Always: 6 (7.4%)
Are youth with cancer and their families introduced to palliative care concepts to support them throughout the disease process regardless of disease status? ^a	None: 0 (0%) Some: 36 (44.4%) All: 37(45.7%)
Are patients and their families provided developmentally appropriate preparatory end-of-life psychosocial care? ^a	Never/rarely: 3 (3.7%) Sometimes: 29 (35.8%) Always: 40 (49.4%)
Does a member of the team contact the family after the child's death to assess family needs and to identify those for negative psychosocial sequelae? ^a	Never: 5 (6.2%) Sometimes: 28 (34.6%) Always: 39 (48.1%)
How often is support provided to the family after a child's death to assess family needs and to provide resources for bereavement support? ^a	<i>Are bereavement services offered on-site or referred to community:</i> No bereavement services are provided: 4 (4.9%) Provide some on-site and refer the rest to the community: 36 (44.4%) Referred to the community: 26 (32.1%) Provided on-site: 5 (6.2%)
How often do you provide bereavement support to a family after a child has died? ^a	Never/rarely: 7 (8.6%) Sometimes: 35 (43.2%) Always: 30 (37.0%)

(Continued)

Table 2. (Continued).

Standard item	Itemized results(<i>N</i> = 81)
How well are psychosocial professionals integrated into pediatric oncology care settings as integral team members? ^a	Never/rarely: 1 (1.2) Sometimes: 13 (16.0%) Always: 60 (74.1%)
Are standardized psychosocial assessment and treatment plan documented in the medical record? ^a	Never/rarely: 16(19.8%) Sometimes: 10(12.3%) Always: 48(59.3%)
What is required of childhood cancer psychosocial providers at your institution regarding specialized education? ^a	None: 3 (3.7%) Some: 18 (22.2%) All: 52 (64.2%)
How many providers have experience with children with serious or chronic illnesses? ^a	None: 5 (6.2%) Some: 27 (33.3%) All: 41(50.6%)
How many providers are credentialed in their discipline? ^a	None: 3 (3.7%) Some: 8 (9.9%) All: 63 (77.8%)

^aSome data were not available for all questions. Percentages are based on the available data.

Assessment of financial hardship (Standard 5)

More than half of the institutions provided financial screenings systematically at diagnosis ($n = 47$, 58.0%) and during treatment ($n = 39$, 48.1%). Systematic financial screenings were less commonly reported during survivorship ($n = 21$, 25.9%) and bereavement care ($n = 12$, 14.8%). A few of the institutions offered support for financial concerns during end of life including referrals to hospice agencies and assistance with funeral expenses. Participants specifically reported referring families for grants, foundation funds, and referrals to financial counselors and agencies in the community.

Assessment of parental mental health needs (Standard 6)

Systematic screening for parental distress was reported to most commonly occur around the time of the child's diagnosis ($n = 49$, 60.5%) with less frequent screening during treatment ($n = 24$, 29.6%), survivorship follow-up ($n = 22$, 27.2%), and after the death of a child (bereavement) ($n = 10$, 12.3%). Only 12 institutions incorporated standardized assessment tools to assess parental mental health with the Patient Health Questionnaire 9 (Kroenke, Spitzer, & Williams, 2001) and the PAT (Kazak et al., 2015) being the most common tools utilized. Psychoeducation, counseling, and expressive and integrative therapy interventions were modalities offered by social workers to address parental distress.

Eight institutions offered psychiatric/psychological consultation services to parents during the child's hospitalization for cancer, but these were limited to parents who demonstrated symptoms of acute psychological distress. Institutions affiliated with adult programs referred parents to the Emergency Room for

Table 3. Reported barriers.

Standard	Barriers
Neuropsychological deficits	<ul style="list-style-type: none"> • The majority of our patients have Medicaid ... which has limited providers who often consequently have long waits • Distance travelled by families • Obtaining baseline screening can be challenging depending on treatment plan and urgency of treatment • Some families do not buy into the need for neuro-psychological testing • Time and staff availability due to other duties and funding issues
Screening for psychosocial functioning for long-term survivors	<ul style="list-style-type: none"> • No formal survivorship program in place • They don't typically get priority due to my high caseload • Patients aren't routinely assessed—only if clinically indicated • I feel it is EXTREMELY important but I feel like I hit a wall when I try to present it
Access to psychosocial support throughout the treatment trajectory	<ul style="list-style-type: none"> • Psychiatry only available between 8–4 • No in-house psychiatry available and there are very few psychiatrists who accept Medicaid in our area • Psychiatry is for inpatients only • Once off treatment, families generally must connect with community-based providers • Some families live in remote areas where interventions may be difficult to access • Those who present with problems get intervention but those who seem ok and do not voice needs do not get as much support • We have one child psychiatrist for the entire health system and the community at large
Access for financial hardship	<ul style="list-style-type: none"> • The majority of our clients are financially at risk prior to diagnosis • There are no systematic/planned financial screenings during treatment, survivorship or bereavement unless a family expresses needs • I rely on the family to tell me if they have a financial need
Assessment of parental mental health needs	<ul style="list-style-type: none"> • Access to psychiatry depends on family's ability to obtain through community or insurance • The waiting list barrier is amplified for our non-English speaking clients • Many families do not follow through with available support recommendations • Psychiatrists do not accept insurance and only are fee for service • Psychologists do not see parents for issues parents are facing—except to offer strategies for helping their child • Consults are made but no ongoing care provided
Education and anticipatory guidance of disease and treatment	<ul style="list-style-type: none"> • There is more anticipatory guidance provided at initial diagnosis, although this is limited by how much information can be absorbed • Due to patient volume, standardized follow-up is not always feasible • There is great variability among clinicians

(Continued)

Table 3. (Continued).

Standard	Barriers
Preparatory interventions for invasive procedures	<ul style="list-style-type: none"> • There is limited child life staffing, especially in the outpatient area • The information is not provided to youth if the parent/guardian requests that it not be shared due to religious beliefs or family preference-usually due to their concern that it could cause unnecessary harm to the patient • Referrals are subjective depending on the physician and family • Sometimes child life is not informed of a procedure and therefore cannot prepare the patient appropriately
Access to social interactions during and after treatment	<ul style="list-style-type: none"> • We are a small center so we don't have someone on treatment in their age group or same diagnosis • Mostly directed to 12–18 year olds • Patients travel long distances to clinic/hospital which creates a barrier to providing these opportunities • We have social support programs 4–6 times per year, but had to stop when they reduced social work hours • We rely on outside community groups • We don't have as many events for our older teenager/young adult population
Sibling support services	<ul style="list-style-type: none"> • Always available but not routinely offered • Families have limited access to transportation and to bring the siblings during the school year is a hardship • Dependent on staff availability, [siblings] attendance in the hospital and at visits • Infection control restrictions don't allow siblings under 12 year of age to visit from October to mid-April • Parents don't wish to return to the hospital in late afternoon or evening for support programming
School reentry support	<ul style="list-style-type: none"> • We only provide resources for schools upon request (maybe 1 in 20 kids, in my experience) • Limited staffing and time prevent schools from receiving support unless specifically asked • Cannot always do this in person because many of our patients are not local
Assessment and monitoring of treatment adherence	Participants included no barriers for the assessment and monitoring for treatment adherence
Palliative and end-of-life support	<p>Palliative care:</p> <ul style="list-style-type: none"> • Dependent on the comfort level of the child's primary oncologist in discussing palliative care • At this time, the team has agreed to do it at relapse or if poor prognosis is evident from the beginning • I don't think at the moment our execution is commensurate with our commitment to palliative care • Depends on patient pain and prognosis • We do a very good job talking about pieces of palliative care without calling it palliative care • All BMT patients are referred to palliative care, but there is no other standard in place <p>End-of-life care:</p> <ul style="list-style-type: none"> • Services not provided if parents object/refuse to allow end-of-life discussions with youth due to their religious beliefs • When prognosis is poor and end-of-life is likely • Subjective depending on the physical condition of the child and willingness of the family • End-of-life care may look somewhat different depending on where the patient lives • It is challenging to talk of end-of-life until the physician starts talking about it-it is typically not accepted by families until the doctor begins the conversation

(Continued)

Table 3. (Continued).

Standard	Barriers
Resources for bereavement support	<ul style="list-style-type: none"> • Many families do not live nearby • There is very limited financial assistance available after death • This is dependent upon whether we are able to get in contact with the family • Staffing limits how much and how often this is done • Families prefer to receive it from their religious support network • Others out of state select someone closer to home • Very few families wish to return to the hospital for support • The [families] have connection with their home institutions and those are generally their point of contact
Provider communication, documentation, and training	<p>Standardized psychosocial assessment and treatment plan are documented in the medical record</p> <ul style="list-style-type: none"> • As my caseload has gotten substantially large, this has been much harder to do • We don't do treatment plans for psychosocial aspect of care • The assessment is documented but may not be read by medical providers • Sometimes the assessment is completed but there is no time to document it—sometimes there is inadequate time to complete the assessment

assessment of needs. Parents most commonly received referrals to community psychiatric services to manage preexisting mental health concerns and medication and for those who had difficulty in coping with their child's illness.

Education and anticipatory guidance for disease and treatment (Standard 7)

Psychoeducation pertaining to the disease and treatment were described as being provided on a regular basis at 67.9% ($n = 55$) of institutions, with fewer providing psychoeducation regularly about hospitalization ($n = 44$, 54.3%), or psychosocial adaptation ($n = 43$, 53.1%). The remainder only provided these services when clinically indicated.

According to the study participants, the majority of psychoeducation is provided by social workers, followed by child life specialists, nurses, and psychologists. Psychoeducation included the provision of resources, including books, the Children's Oncology Group (COG) Family Handbooks, (Keene, 2010; Keene, Hobbie, & Ruccione, 2014; Shiminski-Maher, Woodman, & Keene, 2014; Spurgeon & Keene, 2016), educational support groups, camp programming, and scheduled educational events.

Preparatory interventions for invasive procedures (Standard 8)

Participants reported that preparatory interventions are most often provided by child life specialists for invasive procedures, such as bone marrow, lumbar

punctures, and transplantation. Some institutions drew upon the interdisciplinary team (nurses, physicians, and social workers) to assist the child life specialists in educating the family and providing additional support. Preparatory interventions for invasive procedures were provided on a routine basis ($n = 59$, 72.8%) or when requested ($n = 16$, 19.8%), with only one institution (1.2%) not providing any preparatory guidance.

Access to social interactions (Standard 9)

Approximately one-third ($n = 29$, 35.8%) of the institutions represented in the study “always” offered social activities. Examples of social opportunities included scheduled activities in the inpatient playrooms, support groups, or planned annual hospital socials. Participants described creative opportunities their institutions offered for patients and families to connect with each other. Social outlets included partnerships with community agencies to offer camps, family retreats, and adolescent and young adult-specific activities, bereavement support groups, and memorial services.

Sibling support (Standard 10)

Participants reported offering a variety of services and programs to promote sibling socialization and emotional support. The majority of institutions provided some sibling support ($n = 51$, 63.0%), while about a third of institutions always provided support for siblings ($n = 24$, 29.6%). Participants noted that many families choose not to access these services. The institutions that did not offer sibling support programs ($n = 2$, 2.5%) functioned with limited psychosocial support staff and offered few social interactions for patients and families.

School reentry support (Standard 11)

Participants reported that over half of the institutions always provided school reentry support to parents and children ($n = 44$, 54.3%), with over a third “sometimes” offering these services ($n = 28$, 34.6%). For a little over half of the institutions ($n = 47$, 58.0%), direct support to schools and teachers to help the child transition back into the school system was “sometimes” provided. Many institutions had a dedicated education coordinator, whereas other sites utilized social workers or child life specialists to assist with school reentry. Participants utilized partnerships with community organizations such as the Leukemia and Lymphoma Society’s *Learning and Living with Cancer* program to assist with school reentry needs (Leukemia & Lymphoma Society, 2013).

Assessment and monitoring of treatment adherence (Standard 12)

For 44.4% ($n = 36$) of the institutions, treatment adherence was only assessed when a concern was identified. Once a problem with adherence was noted, participants described performing an assessment to determine patient and family barriers. Interventions included psychosocial approaches, referrals to other psychosocial providers, collaborative approaches with nursing and psychology, and in extreme situations, referrals to Child Protective Services.

Palliative care and end-of-life support (Standard 13)

A limited number of institutions ($n = 6$, 7.4%) consistently provided families with an introduction to palliative care concepts, regardless of the disease status. A larger portion of institutions provided education about palliative care on an occasional basis ($n = 59$, 72.8%). Referrals to palliative care tended to occur when the cancer diagnosis became advanced or when pain or other symptoms became severe. Participants at 11.1% ($n = 9$) of the institutions reported that palliative care concepts were never introduced to children with cancer or their families.

All participants responded that their institutions provide some developmentally appropriate end-of-life psychosocial care, with less than half ($n = 37$, 45.7%) “always” assisting families. End-of-life care most often included an interdisciplinary team approach and partnership with community agencies such as hospices.

Resources for bereavement support (Standard 14)

In 37% ($n = 30$) of the institutions, bereavement support for families “always” occurred following the death of a child. About half ($n = 40$, 49.4%) of the institutions “always” contacted the family after the child’s death to assess family needs. A small number of institutions provided no bereavement support to families ($n = 4$, 4.9%). The remainder offered on site services ($n = 5$, 6.2%), a hybrid of services between the institution and the community ($n = 36$, 44.4%), or offered a referral to community agencies ($n = 26$, 32.1%). The institutions that provided bereavement services on-site incorporated phone calls, mailed cards, or bereavement resource packets and sometimes assisted with financial resources for funeral expenses. Some institutions offered bereavement support groups, counseling, or annual memorial services or weekend retreats.

Provider communication, documentation, and training (Standard 15)

A majority of participants ($n = 60$, 74.1%) reported that they “always” feel they are an integral part of the pediatric oncology team. For 59.3% ($n = 48$) of the participants, their psychosocial assessments and treatment plans are “always” documented in the medical record. None of the participants reported including a standardized assessment tool as part of their documentation in the medical record. Participants at more than half of the institutions reported that all of their psychosocial staff have specialized education ($n = 52$, 64.2%), credentials ($n = 63$, 77.8%), or experience in working with children who have severe or chronic illnesses ($n = 41$, 50.6%).

Barriers

The participants described barriers to implementing the Standards into their day-to-day practice. The barriers included inadequate staffing ratios, lack of institutional support of psychosocial services, and uncertainty about how to implement the Standards because of a lack of guidelines. [Table 3](#) displays quotes from participants about the barriers they experienced in accessing staff and in implementing the Standards.

Discussion

This paper provides results from a survey completed by 107 pediatric oncology social workers from 81 cancer centers. While psychosocial care is provided at all but one institution surveyed, many of the Standards are not currently being systematically implemented. The barriers noted, particularly inadequate staffing, are consistent with findings in another recent publication that surveyed psychosocial leaders, pediatric oncologists, and hospital administrators from 144 programs (Scialla et al., 2017). Both studies find that most children’s hospitals are providing some form of psychosocial services but the lack of adequate time and staffing may contribute to the Standards not being optimally implemented. Scialla et al. (2017) gathered data from administrators and psychosocial providers and leaders and found that the majority of psychosocial services in pediatric oncology care were delivered by social workers and child life specialists. This study builds on Scialla et al. (2017) findings by specifically targeting the input of pediatric oncology social workers and providing their perspective on the implementation of the specific Psychosocial Standards. In a second paper by Scialla et al. (2018), the authors suggested that integrated psychosocial care (including social work, child life, psychology, and psychiatry) was found to be a predictor of comprehensive state of the art care. The discussion is organized by the individual Standards.

Financial needs

There has been increasing evidence of the cumulative family financial hardship associated with caring for a child with cancer (Bona et al., 2014; Bona, London, Guo, Frank, & Wolfe, 2016; Dussel et al., 2011). Caring for a child with cancer often requires time spent in the hospital away from home and work. Additional expenses, such as travel expenses, temporary housing, medications, and treatment co-pays accumulate. As social workers meet most newly diagnosed children and their families, a psychosocial assessment of preexisting financial burden coupled with the known hardships associated with cancer treatment allows for a reasonably comprehensive snapshot of the financial needs of families across the cancer trajectory. Although most institutions assess for financial burden at the time of diagnosis, this assessment happens less frequently during treatment and even less frequently during survivorship and at time of bereavement. This finding has significant relevance for families as emerging literature links financial hardship to parental quality of life and emotional health and demonstrates impact on survival outcomes (Bona et al., 2014, 2016). Social workers need to work with financial counselors to systematically re-examine a family's financial needs from diagnosis, through treatment, into survivorship or bereavement. Social workers are uniquely positioned within the psychosocial team to advocate for and help families navigate the complex financial circumstances they encounter prior to and during treatment. Social workers should also take the opportunity to educate the wider team about the challenges families face while undergoing cancer treatment and the long-term financial implications. Development of universal tools to assess financial burden should be created.

Psychoeducation and education

The diagnosis of cancer is often associated with a challenge to understand new and complicated medical terms. With their child's health in danger, families must quickly grasp information about the disease and treatment procedures. The unfamiliar nature of the hospital is often frightening. Yet, the provision of education and anticipatory guidance around the cancer diagnosis and treatment is a Standard that is not being provided in approximately a third of institutions. Providing patients and their families with anticipatory guidance, information, and psychoeducation throughout the course of the cancer trajectory is an important component of psychosocial care (Beale, Kato, Marin-Bowling, Guthrie, & Cole, 2007; Bingen & Kupst, 2010; Bradlyn, Beale, & Kato, 2003). Social workers play a vital role in helping families to anticipate the changes they will likely encounter across the cancer trajectory. Helping families cope with impact on lifestyle, education, employment, siblings, and family relationships all fall within the scope

of social work practice. As social workers view families through a “person in environment” lens, they are also the discipline most likely to empower families to connect with community and hospital-based resources. Social workers also have a responsibility to ensure that care is culturally sensitive to the diverse backgrounds and to reduce disparities in access to treatment. Barriers to implementing this Standard included low staffing ratios and lack of inclusion of the social worker in initial diagnostic conversations.

The availability of many different models for education increases opportunities for children to maintain their academic achievement during cancer therapy. Distance learning, home schooling, and online learning are a few options that now exist and supplement traditional classroom attendance. While about half of the institutions surveyed offer school reentry programs in the form of assistance at the hospital or connecting with classroom teachers to facilitate successful reentry, many children and adolescents continue to miss a significant amount of time at school impacting their peer and academic development.

Social workers have the capacity to discuss education options with parents, connect with schools, and in some instances, attend meetings with school personnel to educate teachers about the treatment protocols and how treatment will impact attendance. Additionally, linking parents and schools to community agencies that develop resource materials for both parents and educators, such as the Leukemia and Lymphoma Society, American Cancer Society, and the Association of Pediatric Hematology Oncology Education Specialists can aid in school reentry.

Neuropsychology referrals

Cancer treatment and treatment-related side effects often lead to children missing a significant amount of time from school. These absences can impact academic progress and socialization. Neuropsychological follow-up has been identified by the American Academy of Pediatrics Section on Hematology/Oncology Children's Oncology Group (2009) as a critical component to the care of children who have central nervous system cancers and are cancer survivors. Yet, most participants reported that access to neuropsychological services remains very limited. Limited staffing and financial coverage for neuropsychological testing were reported barriers to children receiving this very important service. Advocating for a referral to a neuropsychologist along with the necessary funding is appropriate.

Psychosocial assessment

Social workers, as the discipline meeting most families at the time of diagnosis, have the skills and ability to perform a comprehensive psychosocial assessment of the family's needs. The assessment should be shared with other

team members caring for the child and family. Less than half of the centers are using a *standardized* assessment tool, though they are more likely to be used in larger institutions. The use of evidence-based assessment tools can help facilitate broader acceptance of psychosocial care and more consistent implementation of this Standard.

Psychosocial needs: Child and family

Access to psychosocial support is crucial in addressing psychological distress across the cancer trajectory. As members of an interdisciplinary team, social workers provide comprehensive assessment and interventions for the behavioral health needs of children and families and may refer to psychologists and psychiatrists for additional counseling or medication throughout the care trajectory. Families who live in remote areas may not benefit from such hospital-based services due to limited access to their child's treatment team. Moreover, when children are further out from their treatment, families may not look to their treatment team for help, and community resources may or may not be readily available.

Unfortunately, psychiatry is typically less frequently accessible to families and may result in unaddressed mental health disorders in children and their families. The lack of psychiatrists in many institutions as well as insurance costs for psychiatric assessment and treatment leave a number of parents without the services required to optimize their functioning. Language barriers may also impact the provision of psychosocial care for parents. Institutions need to provide comprehensive psychosocial support, including access to psychiatry services when necessary.

Social interaction

The opportunity for children with cancer to connect with others facing similar challenges often relieves some of the distress and isolation encountered during diagnosis, treatment, survivorship, and bereavement. Only one-third of institutions reported having programs to consistently provide this type of programming. Social workers can be instrumental in educating parents around the importance keeping the child connected to peers through contact with classmates, social media, and referrals to programming available for immune-compromised children. Social workers can also alert the medical team to situations where children's psychological functioning could be impacted by their lengthy hospitalization and isolation. Social workers can also collaborate with child life and psychology colleagues to coordinate solutions and interventions for these children.

Siblings

Siblings of children undergoing cancer treatment are exposed to significant stress. They are often separated from their family due to the geographic distance of the treatment center from home, resulting in decreased contact with family members and disruptions in their day-to-day routine while worrying about the health of their ill sibling. Approximately two-thirds of institutions provide some level of psychosocial care for siblings. Barriers include distance from hospitals, logistical issues for parents in caring for their ill child as well as siblings, and lack of staffing in some instances. Other challenges that prevented siblings from receiving psychosocial support included lack of visitation during flu season, transportation expenses, and timing of most activities during school hours.

Social workers can provide education for parents around the emotional needs of siblings and strategies for the inclusion and preparation of siblings across the cancer treatment trajectory. Developing in-hospital programming, identifying camp experiences for siblings, assisting families with transportation and financial assistance to support sibling care all fall within the domain of social work practice.

Adherence to treatment

The importance of treatment adherence for children with cancer is critical for optimal health outcomes (Bhatia et al., 2012). It is an issue that all team members must pay attention to. Adherence to medication was infrequently reported to be routinely monitored. Achievement of adherence is multifaceted and relies upon many strategies: education, assessment, and patient-directed interventions.

Traditionally, social workers have been consulted when nonadherence is identified. Social workers serve an important role in assessing the families' reasons for nonadherence and where feasible, removing barriers. Social workers can help to increase treatment adherence by helping the team understand whether the nonadherence is due to lack of knowledge, psychological reasons, or practical/financial problems.

Survivorship

Children who complete treatment for cancer have a high risk of both medical and psychosocial late effects in survivorship (Dickerman, 2007; Lipshultz et al., 2012; Neglia et al., 2001; Sklar et al., 2000). The Children's Oncology Group (2014) publishes Survivorship Guidelines every three years that detail suggestions for identifying physical and psychosocial risks in long-term pediatric cancer survivors. Recognizing that long-term survivors of childhood cancer are

known to be at risk for developing social, educational, vocational, psychological, and behavioral problems, psychosocial screening of these survivors is crucial. It is encouraging to note that in more than half of the institutions social workers reported routine monitoring is being offered, either in formal long-term survivorship clinics or as part of follow-up during clinic visits. Social workers are able to assess whether survivors are well integrated into their communities of work, school, and peer group and can develop individualized interventions such as counseling to support adjustment, peer-matching, and referrals to online groups and camps. Talking with survivors about challenges they face will guide intervention within the team or facilitate referral to the community for counseling around those issues that may not be as a result of cancer therapy. Social workers can also, along with the interdisciplinary team, provide transition support for children and families as they complete treatment.

Palliative and end-of-life care

Increasing evidence is mounting that children with cancer and their families should be introduced to palliative care concepts early in their disease trajectory to facilitate adjustment to the diagnosis, increase understanding of complicated treatment plans, manage disease symptoms, and reduce emotional, spiritual, and physical suffering, regardless of prognosis (Pritchard, Cuvelier, Harlos, & Barr, 2011; Rosenberg & Wolfe, 2013; Weaver et al., 2016; Waldman & Levine, 2016). In spite of the acknowledgment of these principles, only 7.4% of institutions always provide an introduction to palliative care concepts regardless of disease status and 11.1% reported that palliative care concepts were never introduced. Many barriers remain, including institutional, with a lack of available pediatric palliative care specialists, lack of time or resources for reimbursement, and lack of clarity about the scope of palliative care; it is often synonymous with end of life and is not introduced until treatment is no longer effective (Jones, 2005; Rosenberg & Wolfe).

Many of the survey participants reported that discussions about palliative care were not as prevalent as they wished they could be, with noted barriers being the stigma attached to palliative care and the dependency on physicians to initiate a palliative care referral. Early integration of palliative care concepts allows for effective, honest, and empathic communication wherein families can share their preferences for their child, share decision-making, and improve the quality of life for patients and their families across the illness trajectory (Rosenberg, Wolfe, & Jones, 2016).

Social workers, as integral team members, have opportunities to facilitate interdisciplinary discussions around early integration of palliative care concepts. Social workers can encourage team members to initiate conversations

with families at the time of diagnosis to better understand their goals and values, and to determine the level of support they may require regardless of the course of the child's treatment.

If cure is not possible, social workers have a meaningful and significant role with children and families, including helping with the provision of timely, accurate information and support in decision-making, remaining present and open to a range of emotional reactions and unfolding questions, emotionally supporting the child and family, facilitating conversations between the child, family, and medical team. Social workers can work closely with parents to anticipate and address the emotional and practical needs of each family member. As death nears, social workers can support families by providing ongoing consistent support, helping to provide concrete resources, facilitating conversations about legacy and remembrance, and providing specific information about the financial and practical implication of funeral arrangements. Social workers may guide conversations with teams around end-of-life care being culturally or spiritually sensitive. Social workers can also provide consistent, compassionate support while helping the child and family have as much control as possible (Jones, 2005).

Bereavement

After the death of a child, families experience physical, emotional, social, and spiritual distress (Meert, Thurston, & Briller, 2005; Steele et al., 2013). Parents often desire a continued connection to their child's treatment team and may feel abandoned and isolated if there is no contact following their child's death. Many parents view the staff as their support network and experience the loss of those relationships in addition to the loss of their child (Lichtenthal et al., 2015). Social workers can assess bereavement needs and organize bereavement programs such as remembrance services, facilitate grief groups for parents and siblings, and provide bereavement counseling. Lack of funding for social workers to follow up with families following the death of their child was a noted barrier. When a social worker is not able to provide direct bereavement support to a family, a referral should be facilitated to a support resource within the family's community.

Interdisciplinary collaborations

Professional training, respectful communication and collaboration among medical and psychosocial providers, patients and families, and access to and the sharing of relevant reports between healthcare providers are key to successful delivery of quality psychosocial services. Fortunately, the majority of social work participants reported that they perceive themselves to be an integral part of the oncology team. Given their specialized training, social workers may

provide education for the rest of the medical team in communication skills so that the information presented is sensitive, honest, and shared with empathy and compassion. Implementing the psychosocial Standards, like psychosocial care in general, is an interdisciplinary responsibility that requires the explicit engagement and support of all members of the care team and administration (Wiener, Kazak, Noll, Patenaude, & Kupst, 2015b).

Limitations

While this study provides important information from the perspective of social workers on the implementation of the Pediatric Psychosocial Standards, there are noted limitations. Programs were requested to provide one respondent per site; however, we encountered multiple responses from 17 institutions. The survey relied on self-report that can lead to an inherent bias of over- or under-reporting the degree to which the Standards were being implemented. Perspectives are also limited to a snapshot in time when the survey was distributed. The results do not capture the level/quality of care provided in delivery of each Standard. Future research should include a longitudinal view of the Standards and gather the experiences of children and families themselves, whether they perceive the Standards are being offered at their treatment site and if these services have an impact on their outcomes and quality of life.

Conclusion

The 2015 Psychosocial Standards of Care for Children with Cancer and their Families were created to standardize the delivery of psychosocial care to all children with cancer and their family members. The findings suggest that there is room for improvement for consistent implementation of the Standards. Currently, there are no guidelines to help institutions implement the Standards and measure their impact. As advocates for children with cancer and their families, social workers are well positioned to assist in the development of guidelines and to advocate for the optimal delivery of the psychosocial Standards in every pediatric institution where they work.

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Appendix A. Survey questions

Approximate number of childhood cancer patients treated at your site annually?
 How many social workers at your site provide services to pediatric patients?
 How many psychologists at your site provide psychosocial services to pediatric cancer patients?
 How many psychologists at your site provide neuropsychological testing to pediatric cancer patients?
 Is a process in place for youth with cancer and their families to receive assessments of their psychosocial healthcare needs?
 When do patients with brain tumors (and others at high risk for neuropsychological deficits as a result of their cancer treatment) receive for monitoring neurological-psychological deficits?
 How frequently do long-term survivors of child and adolescent cancers receive psychosocial screenings for adverse education and/or vocational progress and relationship difficulties?
 How frequently do long-term survivors of child and adolescent cancers receive psychosocial screenings for distress, depression and anxiety?
 How frequently do long-term survivors of child and adolescent cancers receive psychosocial screenings for risky health behavior?
 Do youth have access for psychosocial support interventions throughout cancer trajectory?
 Availability of psychiatrists?
 Does your institution provide on-site mental health care for parents?
 How often is the risk for financial hardship assessed for pediatric oncology families?
 How often are parents of children with cancer assessed for their mental health needs?
 Are there standardized measures used to assess parents/caregivers' mental health concerns?
 How often do youth with cancer and their family members receive psychoeducation, information, and anticipatory guidance?
 What opportunities for social interaction with others their age are provided to children and adolescents during treatment and/or survivorship?
 How often are siblings of children with cancer provided with psychosocial support and interventions?
 How often are the following groups provided with support for the reentry of a childhood cancer patient into school?
 How is adherence assessed and monitored throughout treatment?
 Are youth with cancer and their families introduced to palliative care concepts to support them throughout the disease process regardless of disease status?
 Are patients and their families provided developmentally appropriate preparatory end-of-life psychosocial care?
 Does a member of the team contact the family after the child's death to assess family needs and to identify those for negative psychosocial sequelae?
 How often is support provided to the family after a child's death to assess family needs and to provide resources for bereavement support?
 How often do you provide bereavement support to a family after a child has died?
 How well are psychosocial professionals integrated into pediatric oncology care settings as integral team members?
 Are standardized psychosocial assessment and treatment plan documented in the medical record?
 What is required of childhood cancer psychosocial providers at your institution regarding specialized education?
 How many providers have experience with children with serious or chronic illnesses?
 How many providers are credentialed in their discipline?

Appendix B. Standards of Pediatric Psychosocial Care for Children with Cancer and Their Families

1. Youth with cancer and their family members should routinely receive systematic assessments of their psychosocial healthcare needs.
2. Patients with brain tumors and others at high risk for neuropsychological deficits as a result of cancer treatment should be monitored for neuropsychological deficits during and after treatment.
3. 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; (b) distress, anxiety, and depression; and (c) risky health behaviors. Adolescent and young adult survivors and their parents should receive anticipatory guidance on the need for lifelong follow-up care by the time treatment ends and repeated at each follow-up visit.
4. Youth with cancer and their family members should have access to psychosocial support and interventions throughout the cancer trajectory and access to psychiatry as needed.
5. Pediatric oncology families are at high risk for financial burden during cancer treatment with associated negative implications for quality of life and parental emotional health. Assessment of risk for financial hardship should be incorporated at time of diagnosis for all pediatric oncology families. Domains of assessment should include risk factors for financial hardship during therapy including preexisting low-income or financial hardship, single parent status, distance from treating center, anticipated long/intense treatment protocol, and parental employment status. Targeted referral for financial counseling and supportive resources (including both governmental and charitable supports) should be offered based on results of family assessment. Longitudinal reassessment and intervention should occur throughout the cancer treatment trajectory and into survivorship or bereavement.
6. Parents and caregivers of children with cancer should have early and ongoing assessment of their mental health needs. Access to appropriate interventions for parents and caregivers should be facilitated to optimize parent, child, and family well-being.
7. Youth with cancer and their family members should be provided with psychoeducation, information, and anticipatory guidance related to disease, treatment, acute and long-term effects, hospitalization, procedures, and psychosocial adaptation. Guidance should be tailored to the specific needs and preferences of individual patients and families and be provided throughout the trajectory of cancer care.
8. Youth with cancer should receive developmentally appropriate preparatory information about invasive medical procedures. All youth should receive psychological intervention for invasive medical procedures.
9. Children and adolescents with cancer should be provided opportunities for social interaction during cancer therapy and into survivorship following careful consideration of the patients' unique characteristics, including developmental level, preferences for social interaction, and health status. The patient, parent(s), and a psychosocial team member (e.g., designee from child life, psychology, social work, or nursing) should participate in this evaluation at time of diagnosis, throughout treatment, and when the patient enters survivorship; it may be helpful to include school personnel or additional providers.
10. Siblings of children with cancer are a psychosocially at-risk group and should be provided with appropriate supportive services. Parents and professionals should be advised about ways to anticipate and meet siblings' needs, especially when siblings are unable to visit the hospital regularly.
11. In collaboration with parents, school-age youth diagnosed with cancer should receive school reentry support that focuses on providing information to school personnel about the patient's diagnosis, treatment, and implications for the school environment and provides recommendations to support the child's school experience. Pediatric oncology programs should identify a team member with the requisite knowledge and skills who will coordinate communication between the patient/family, school, and the healthcare team.
12. Adherence should be assessed routinely and monitored throughout treatment.
13. Youth with cancer and their families should be introduced to palliative care concepts to reduce suffering throughout the disease process regardless of disease status. When necessary youth and families should receive developmentally appropriate end-of-life care (which includes bereavement care after the child's death).
14. A member of the healthcare team should contact the family after a child's death to assess family needs, to identify those for negative psychosocial sequelae, to continue care, and to provide resources for bereavement support.

(Continued)

(Continued).

15. Open, respectful communication and collaboration among medical and psychosocial providers, patients and families is essential to effective patient- and family-centered care. Psychosocial professionals should be integrated into pediatric oncology care settings as integral team members and be participants inpatient care rounds/meetings.

Pediatric psychosocial providers should have access to medical records and relevant reports should be shared among care team professionals, with psychological report interpretation provided by psychosocial providers to staff and patients/families for patient care planning. Psychosocial providers should follow documentation policies of the health system where they practice in accordance with ethical requirements of their profession and state/federal laws.

Pediatric psychosocial providers must have specialized training and education and be credentialed in their discipline to provide developmentally appropriate assessment and treatment for children with cancer and their families. Experience working with children with serious, chronic illness is crucial as well as ongoing relevant supervision/peer support.

From Wiener et al. (2015a).