

RESEARCH ARTICLE

Implementing the psychosocial standards in pediatric cancer: Current staffing and services available

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Abstract

Background: Fifteen evidence-based Standards for Psychosocial Care for Children with Cancer and Their Families (Standards) were published in 2015.¹ The Standards cover a broad range of topics and circumstances and require qualified multidisciplinary staff to be implemented. This paper presents data on the availability of psychosocial staff and existing practices at pediatric oncology programs in the United States, providing data that can be used to advocate for expanded services and prepare for implementation of the Standards.

Procedure: Up to three healthcare professionals from 144 programs (72% response rate) participated in an online survey conducted June–December 2016. There were 99 pediatric oncologists with clinical leadership responsibility (Medical Director/Clinical Director), 132 psychosocial leaders in pediatric oncology (Director of Psychosocial Services/Manager/most senior staff member), and 58 administrators in pediatric oncology (Administrative Director/Business Administrator/Director of Operations). The primary outcomes were number and type of psychosocial staff, psychosocial practices, and identified challenges in the delivery of psychosocial care.

Results: Over 90% of programs have social workers and child life specialists who provide care to children with cancer and their families. Fewer programs have psychologists (60%), neuropsychologists (31%), or psychiatrists (19%). Challenges in psychosocial care are primarily based on pragmatic issues related to funding and reimbursement.

Conclusion: Most participating pediatric oncology programs appear to have at least the basic level of staffing necessary to implement some of the Standards. However, the lack of a more comprehensive multidisciplinary team is a likely barrier in the implementation of the full set of Standards.

KEYWORDS

pediatric oncology, psychosocial, standards of care

1 | INTRODUCTION

A robust evidence base demonstrates that children with cancer and their family members experience the diagnosis of cancer as one of the most stressful life events, and that diagnosis is the beginning of intense and often difficult treatment decisions and experiences, with short- and long-term implications for well-being.² Psychosocial providers, such as social workers and psychologists, have a long history of

collaboration with medical colleagues in providing and researching multidisciplinary care models to treat children with cancer and their families.³ However, parents and professionals alike recognize that the psychosocial care provided is often inadequate to address the concerns of patients and families.^{4–6}

Recognizing the need to standardize the delivery of psychosocial care to ensure that all families receive the best care available, the multidisciplinary Psychosocial Standards of Care Project for Childhood Cancer (PSCPCC), supported by the Mattie Miracle Foundation (www.mattiemiracle.com), was formed in 2012, consisting of more than 80 oncology professionals and parent advocates. Over 3 years, the PSCPCC developed a set of 15 evidence-based Standards for Psychosocial Care for Children with Cancer and Their Families¹

Abbreviations: COG, Children's Oncology Group; EHR, electronic health record; FTE, full-time equivalent; NCI, National Cancer Institute; NCORP, National Cancer Institute Community Oncology Research Program; PSCPCC, Psychosocial Standards of Care Project for Childhood Cancer; REDCap, Research Electronic Data Capture; Standards, Standards for Psychosocial Care for Children with Cancer and Their Families

(Standards; Supplementary Material S1). These standards cover a broad range of psychosocial care from diagnosis through survivorship or end of life. The provision of these services, which include attention to clinical issues such as pain,^{7,8} adherence to treatment,⁹ and school issues¹⁰ among others, is recognized as critical to providing comprehensive family-centered care to children and their families.^{11–13} The Standards are endorsed and/or supported by key professional groups (Supplementary Material S1).

With its history of attention to the psychosocial needs of patients and families, pediatric cancer can be an exemplar for other pediatric populations. The effective assessment and delivery of care that addresses child and family psychosocial risks and social determinants of health are critical issues in pediatrics.^{14,15} They require a qualified multidisciplinary psychosocial workforce to provide effective and timely integrated psychosocial care. Unfortunately, even in cancer, there is a lack of information about the availability of psychosocial staff and services at the breadth of treatment programs around the country. In a previous study of Children's Oncology Group (COG) member institutions, there were some expected relationships between the size of the cancer program and staff size.¹⁶ However, size was unrelated to the percentage of families who were offered psychosocial support and there was minimal utilization of standardized assessment tools or evidence-based treatment approaches. This suggests that universal implementation of the Standards may be challenging, as there is likely great variability in terms of particular sites' readiness to move forward to meet the Standards.

This study reports the number, type, and availability of multidisciplinary psychosocial staff at U.S. pediatric oncology treatment programs. While beyond the scope of this paper to address in detail, in general, psychosocial staff include primarily social workers, psychologists, psychiatrists, and child life specialists, each with a specific skill set that is necessary for comprehensive psychosocial care. Data are also provided on access to psychosocial care—when it is first delivered, to whom it is provided, and how psychosocial staff practice as members of the oncology team. Challenges and barriers to psychosocial care are also presented. The relationship between size of the programs and National Cancer Institute Community Oncology Research Program (NCORP; <https://ncorp.cancer.gov>) status (component/subcomponent or not) and the major outcomes were also explored.

2 | METHOD

2.1 | Study design, sample, and recruitment

A national survey open to all pediatric oncology treatment programs in the United States ($n = 200$)—*Preparing to Implement Psychosocial Standards: Current Services and Staffing (PIPS-CSS)*—was conducted from June to December 2016. The Checklist for Reporting Results of Internet E-Surveys (CHERRIES; Supplementary Table S1) was used in reporting the study design and methodology.¹⁷ Although the unit of analysis is the pediatric oncology program, extensive efforts were undertaken to assure independent assessments from up to three specific oncology professionals with leadership roles at each

program—a pediatric oncologist (Medical Director/Clinical Director), a psychosocial leader (Director of Psychosocial Services/staff member with most seniority), and an administrator (Administrative Director/Business Administrator/Director of Operations).

Initial contact was made by the Principal Investigator (AEK) via email introducing the study and identifying and confirming participants. Each program contributed up to three participants—one oncologist, one psychosocial leader, and one administrator. While programs were limited to up to three participants (only one from each discipline), participants were encouraged to collaborate with other team members to ensure accurate and complete answers. Survey data were collected and managed electronically by Research Electronic Data Capture (REDCap).¹⁸ The survey was voluntary and confidential, and accessible only to those who were provided a link. A personalized email that contained a unique survey link and a link to the informed consent document was sent to each identified person. Automated reminder emails were sent with additional personal follow-up emails. Sites completing all three versions (oncologist, psychosocial staff, administrator) were entered in a drawing for a complimentary copy of a new textbook on psychosocial care in pediatric cancer.¹⁹ All study procedures were reviewed by the Nemours Institutional Review Board, which granted a waiver of documentation of informed consent, and determined the study to be exempt from further Institutional Review Board review.

2.2 | Survey instrument

The initial survey was written by the Principal Investigator (AEK) and reviewed by the leadership team of the PSCPC, three pediatric oncologists, and two parent advocates. The survey was refined based on review by faculty with expertise in survey research methods, psychosocial care, and/or pediatric oncology, as well as an experienced nurse site coordinator. The study team further refined the survey, and subsequent revisions to the questionnaire were further reviewed by a psychologist, social workers, an oncology administrator, child psychiatrist, and child life specialist. The survey was pilot tested for usability, technical functionality, clarity of items, and length.

The final survey includes sections on participant demographics, program characteristics, and psychosocial staff characteristics. The survey included a series of questions about when psychosocial care is provided, to whom it is provided, and how psychosocial staff practice as members of the oncology team. Specifically, these items addressed whether psychosocial care is provided to all patients and families or provided only on referral, when care is first provided, and whether psychosocial staff participate in multidisciplinary team activities (e.g., medical rounds, patient care conferences, psychosocial rounds). Additional questions related to providing consultation and training to the healthcare team and documentation of care in the electronic health record (EHR). Challenges and barriers were also queried, including those related to conceptual and organizational issues (lack of medical team support, lack of evidence-based approaches, perceptions of the importance of psychosocial care, hospital organizational structure, and politics) and pragmatic concerns (funding, lack of psychosocial staff, time, reimbursement).

The survey uses Likert-type scales, force-choice responses, and open-ended text responses and employs adaptive questions using branching logic, skip logic, and prompt logic. The number of questions varied based on the role of participant, and by answers to previous questions. The survey included 35–40 questions over 5 screens (administrators), 85–86 questions on 23 screens (oncologists), and 112–150 items on 29 screens (psychosocial leaders). The surveys were completed in an average of 5 (administrator), 10 (oncologist), and 15 min (psychosocial leader). Server-side data quality and validation procedures within REDCap were utilized to minimize missing and/or erroneous data, including designating all items as mandatory and presenting participants with pop-up box prompts indicating missing responses. Participants were not able to review and change answers from previous screens. They could save their progress and return to the survey later using a unique return code. IP addresses and cookies were not stored or utilized; the individualized link prevented duplicate entries. A log file and audit trail was maintained in REDCap.

2.3 | Data analysis

Data were analyzed in January–March 2017. Survey responses were collected and maintained in REDCap and imported into SPSS (version 24; IBM SPSS Statistics). Four submitted surveys were blank (respondents consented, but did not complete any items) and were excluded from analysis. In some cases, incomplete programs were removed from specific analyses (e.g., programs with only an oncologist survey were excluded from analysis of psychosocial staff size, as those data were collected only from the psychosocial leader).

Data from the closed-ended items—size, composition of staff, delivery models, and challenges were analyzed descriptively. For a subset of programs for which program size data (number of new patients in 2015) were available, four groups (<50, 51–100, 101–250, >250) were compared. Participating programs that were NCORP pediatric components/subcomponents were identified using the COG NCORP Committee list. Twenty-five of the 39 (64.1%) NCORP components/subcomponents participated in this study. Differences in these outcomes based on program size were tested using ANOVA. Variations based on NCORP status were tested using independent sample *t*-tests or chi-squares.

3 | RESULTS

3.1 | Participants

Responses were obtained from 144 programs, with an institutional response rate of 72% (Table 1). Based on comparable data available in the COG Institutional Report Cards for 2015, the participating programs were representative of pediatric cancer programs in terms of program size, type of healthcare setting, and geographic location. Participants were oncologists (*n* = 99, 34.3%), psychosocial leaders (*n* = 132, 45.7%), administrators (*n* = 58, 20.1%). In some cases (*n* = 47, 16.3%), the administrative data were provided by an oncologist or psychosocial staff member. One hundred and nine (75.7%) programs

TABLE 1 Characteristics of participants (*n* = 289) and participating programs (*n* = 144)^a

	N (%)
Participant discipline	
Oncologist	99 (34.3)
Psychosocial leader ^b	132 (45.7)
Administrator	58 (20.1)
Multi-role ^c	47 (16.3)
Time posttraining	13 years (median)
Gender (female)	205 (70.9)
Race/ethnicity	
White	243 (84.1)
Black	7 (2.4)
Asian	22 (7.6)
Hispanic	11 (3.8)
No response	6 (2.1)
Geographic distribution (U.S. Census regions) ^d	
Northeast	29 (20.1)
Midwest	32 (22.2)
South	55 (38.2)
West	28 (19.4)
Program size—new pediatric oncology patients in 2015 (total <i>n</i> = 91)	
<50	24 (26.4)
51–100	30 (33.0)
101–250	22 (24.2)
250+	15 (16.5)
Type of healthcare setting (total <i>n</i> = 99)	
Freestanding children's hospital	29 (29.3)
Embedded children's hospital	41 (41.4)
Cancer center	6 (6.1)
Academic medical center	17 (17.2)
Other	6 (6.1)

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

^bThis group consisted of social workers (64), psychologists (57), child life specialists (4), psychiatrists (3), and other psychosocial staff (5).

^cIn some cases, administrative data were provided by the oncologist or psychosocial leader.

^dThe following states had one or more programs represented in the study: AL, AK, AZ, AR, CA, CO, CT, DE, FL, GA, HI, IL, IN, IA, KY, LA, ME, MD, MA, MI, MN, MS, MO, NC, NE, NH, NJ, NM, NV, NY, OH, OK, OR, PA, RI, SC, TN, TX, UT, VA, VT, WA, WI, WV.

returned data from more than one participant. Sixty-one (42.4%) programs returned complete data from all three. A total of 293 surveys were submitted and 254 were complete (respondents submitted a response to the final question on the survey) representing an 86.7% completion rate.

3.2 | Number and type of psychosocial staff

Most programs (95.9%) have a social worker with a Master's Degree and a child life specialist/recreational therapist (93.4%) on staff, with fewer programs including a psychologist (60.3%), neuropsychologist

TABLE 2 Psychosocial staff providing clinical care in U.S. pediatric oncology programs (n = 121)^a

Discipline ^b	In our program	Mean ^c	Median ^c	Range ^c	Spanish speaking
Social workers (MSW)	116 (95.9%)	2.7	2.0	0.0–24.0	35 (28.9%)
Psychologists	73 (60.3%)	1.2	1.0	0.0–9.0	12 (9.9%)
Neuropsychologists	37 (30.6%)	0.4	0	0.0–4.0	– ^d
Psychiatrists	23 (19.0%)	0.2	0	0.0–3.0	2 (1.7%)
Child life specialists	113 (93.4%)	2.4	2.0	0.0–20.0	20 (16.5%)

^aReported by psychosocial leaders.^b75 (62%) programs indicated including disciplines other than the above as part of the psychosocial team, including: chaplains, creative art therapists, educational liaisons, hospital teachers, integrative medicine, nutrition and wellness coordinators, palliative care coordinators, parent support coordinators, navigators.^cReported as full-time equivalents (FTEs).^dNeuropsychologists were combined with psychologists for this question.**TABLE 3** Number of psychosocial staff providing clinical care in pediatric oncology programs by size of program

Staff ^a	Number of new patients (2015)				F	P
	<50 (n = 19) Mean (SD)	50–100 (n = 28) Mean (SD)	101–250 (n = 20) Mean (SD)	>250 (n = 13) Mean (SD)		
Social workers (MSW)	1.18 (0.8)	1.96 (1.17)	3.01 (1.51)	7.87 (6.46)	17.13	0.000
Psychologist	0.61 (0.92)	0.73 (0.79)	1.48 (1.41)	4.02 (2.24)	22.16	0.000
Neuropsychologist	0.11 (0.46)	0.33 (0.61)	0.65 (0.67)	1.48 (1.24)	10.37	0.000
Psychiatrist	0.21 (0.63)	0.02 (0.62)	0.24 (0.52)	0.52 (0.83)	2.70	0.052
Child life specialist	1.34 (0.91)	1.50 (0.78)	2.45 (1.43)	6.88 (5.28)	18.71	0.000

^aNumbers are expressed as full-time equivalents (FTEs).

(30.6%), or psychiatrist (19%) as members of their psychosocial team (Table 2). Based on median values, a “typical” program has two social workers, one psychologist, and two child life specialists. In terms of staff to new patient ratios (median values), there are approximately one full-time equivalent (FTE) social worker (master of social work) per 40 patients; one FTE psychologist per 90 patients; one FTE neuropsychologist per 164 patients; one FTE psychiatrist per 350 patients; and one FTE child life specialist per 50 patients. Only 47 (38.8%) programs reported having at least one Spanish speaking psychosocial team member. Many programs (62%) reported other disciplines on the team, most frequently: chaplaincy/pastoral care, palliative care, creative art therapists, and educational specialists.

A one-way ANOVA was conducted to compare the four sizes of programs with the average number of psychosocial staff (Table 3). The effect was significant for social workers, psychologists, neuropsychologists, and child life specialists. Post hoc comparisons using the Tukey honest significant difference (HSD) test indicated that the average number of psychosocial staff in the largest programs (>250 new patients) was significantly bigger than in all other programs. For psychiatrists, the effect was marginally significant. There were no significant differences in number and type of psychosocial staff by those centers that were NCORP (community research sites) versus those who were not.

3.3 | Psychosocial care practices

Social workers and child life specialists provide care to *all* families at most programs (82.6% and 72%, respectively), while services are rendered largely on referral for psychologists and psychiatrists (59.1%, 64.4%; Table 4). Social workers provide care on the first day

(diagnosis) at less than half of the programs (44.7%). However, at most programs, psychosocial care is delivered by both social workers (84.9%) and child life specialists (77.2%) within 1 week of diagnosis. At the majority of programs, psychosocial staff attend medical rounds (71.9%) and patient care conferences (83.3%), provide consultation to staff (88.6%), and enter notes in the EHR (89.4%). There are rounds specific to psychosocial care at just over half the programs (56.8%), as well as regular psychosocial team meetings (56.8%), and training for the broader healthcare team (53.8%). There were no significant differences in practice variables by size of program or NCORP status.

3.4 | Challenges and barriers

The major barriers to psychosocial care were related to pragmatic concerns, specifically funding for psychosocial staff positions, lack of psychosocial staff, reimbursement of care, and lack of time to provide care (Table 5). More conceptual and organizational issues, such as the importance of psychosocial care, the support of the medical team, lack of evidence-based practices, and hospital organizational structure and politics were less often seen as challenges. There were no significant differences in perceived challenges and barriers by size of program or NCORP status.

4 | DISCUSSION

This paper provides data not previously available that establish a baseline measurement for the current psychosocial staffing structure at pediatric oncology programs in the United States. The data are compelling in highlighting rather skeletal staffing across centers, which

TABLE 4 Multidisciplinary psychosocial care practices in U.S. pediatric oncology programs^a (n = 132)

Practice	Number (%)
Access to care	
Provides care to all patients and families	
Social workers	109 (82.6)
Psychologists	19 (14.4)
Child life specialists	95 (72)
Psychiatrists	2 (1.5)
Provides care on referral	
Social workers	24 (18.2)
Psychologists	78 (59.1)
Child life specialists	30 (22.7)
Psychiatrists	85 (64.4)
Psychosocial care first provided (social worker)	
First day (diagnosis)	59 (44.7)
Within 1 week	53 (40.2)
Psychosocial care first provided (child life)	
First day (diagnosis)	46 (34.8)
Within 1 week	56 (42.4)
Integration in oncology team	
Attend medical rounds	95 (72)
Attend patient care conferences	110 (83.3)
Meet regularly as a team	75 (56.8)
Attend psychosocial rounds	75 (56.8)
Provide consultation to team	117 (88.6)
Provide training to team members	71 (53.8)
Enter notes in EHR	118 (89.4)

^aData were provided by psychosocial leaders.

brings into question the feasibility of implementing the Standards. They can be used to advocate for the support of psychosocial care and multidisciplinary teams more generally. The data show that social workers and child life specialists form the backbone of psychosocial care at responding programs. In general, social workers are front line providers and address social factors impacting the delivery of care. Child life specialists provide child-focused play-based interventions and support to children during treatment and procedures. These two disciplines usually provide care to the majority of families in their programs and do so early in the treatment process (first week), although not necessarily on the first day.

Psychosocial services are interrelated, and there is the potential for some overlap of the care provided by different disciplines. However, comprehensive psychosocial care consistent with the Standards and models of care such as the Pediatric Psychosocial Preventative Health Model²⁰ is compromised by the absence of a truly multidisciplinary psychosocial team,²¹ one including psychologists, neuropsychologists, and psychiatrists, at all but the largest programs. The lack of access to multidisciplinary professionals makes it difficult to implement Standards related to pain,^{7,8} neurocognitive effects of treatment,²² and mental health^{23,24} and to fully implement models of care that require specialized interventions.²⁰ Although psychiatrists were available in

TABLE 5 Challenges and barriers to psychosocial care in pediatric oncology (n = 132)

	Mean (SD)	Median
Conceptual/organizational		
Psychosocial care is not essential	1.27 (0.66)	1
Lack of medical team support	1.62 (0.81)	1
Lack of evidence-based psychosocial approaches	1.63 (0.81)	1
Hospital organizational structure and politics	2.5 (1.08)	2
Pragmatic		
Funding for psychosocial positions	3.36 (0.98)	4
Lack of psychosocial staff	2.8 (1.06)	3
Time to provide psychosocial care	2.68 (1.03)	3
Services not being reimbursable	2.42 (1.14)	2

All challenges/barriers were rated by psychosocial leaders on a 1–4 scale, with 1 indicating “not a challenge/barrier.”

most cases on a consultation basis, they were members of the psychosocial team in less than 20% of programs, a finding that did not vary by size of the institution.

In terms of access to care, most children and families are not seen on the first day of diagnosis. The diagnostic meeting is an extremely difficult event for families; psychosocial assessment and intervention can begin at this early point to support the child and family in navigating the treatment ahead.²⁵ Perhaps more importantly, although the majority of programs report that social workers and child life specialists are seeing all families, not all programs are indicating this. It might be argued that anything less than 100% access is not adequate. There is also the potential for broad interpretation and wide variation in level of service associated with seeing all families (e.g., “checking in” vs. assessment and/or intervention). In addition, relatively few psychosocial staff members speak Spanish, raising questions about the extent to which comparable quality psychosocial care is being provided to families who may need to have information and interventions in a language other than English, and highlighting health inequities in pediatric cancer.^{26,27}

Although the size of the psychosocial team was related to the size of the cancer program, the number and composition of staff alone does not necessarily signal the quality of care. A small, well-integrated team could certainly deliver high-quality, family-centered psychosocial care consistent with the Standards, which may explain the similarities in psychosocial care delivery across programs, regardless of size, and the lack of differences between the NCORP and other sites. There is much to be learned in cancer and other diseases, in terms of how to structure the delivery of integrated psychosocial care and assess its impact on relevant outcomes. There are, for example, similar processes underway in diabetes²⁸ and cystic fibrosis,²⁹ where standards have been developed and are in the process of being implemented.

The data are, in some ways, quite optimistic and warrant some important provisos. Although the response rate in this study was very positive at 72%, it is likely that some nonresponding programs have fewer psychosocial staff members. There could also be a response or social desirability bias. We recognized in evaluating the data that there was a range of models of care and that some psychosocial staff had

competing demands on their time and may not be easily accessible to patients and families. Programs reported their clinical psychosocial staff by FTEs. However, some programs indicated that members of their psychosocial staff are shared with other departments/services. What is less clear from these data is how that portion of time is allocated, and if those psychosocial staff are always available when needed. The survey design, which relied on three respondents per program answering separate question sets, was not feasible for all programs. By including administrators in the survey, we anticipated getting valid data on the size of program (number of new patients) and the sources of funding for psychosocial care. Analyses on these data were therefore limited to the subset of programs for which these data were available. We also observed that staffing (both medical and psychosocial) at programs can change and hospitals are experiencing a rapidly changing healthcare environment and related mergers and altered affiliations. These changes can have a direct impact on the model of care and services provided. It is also important to expand these data by incorporating programs outside the United States in these efforts.

Similarities across programs, in terms of both psychosocial care delivery and perceived challenges and barriers associated with the provision of psychosocial care, indicate that a more systematic and policy-driven approach may be needed to encourage the expansion of existing psychosocial services, and to ensure full implementation of standards in cancer and other conditions. The challenges faced by the majority of programs are operational (funding, staff, billing). These are not trivial concerns but ones that can be addressed by the engagement of all stakeholders (e.g., healthcare administrators, parent advocates, insurance companies, policymakers) in developing innovative solutions related to integrated care and bundled outcome driven reimbursement models. Additional research is necessary to focus on identifying the challenges specifically associated with needed practice change in order to expand existing staff and services needed to fully implement care consistent with the standards, as well as the identification of potential "model programs" to assist others in their implementation efforts.

5 | CONCLUSIONS

This survey study describes the readiness of pediatric oncology programs to implement psychosocial care consistent with the Standards.¹ While most programs have a social worker and child life specialist and larger programs generally have larger psychosocial teams, multidisciplinary staff necessary to implement care consistent with the Standards is often lacking.

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CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

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SUPPORTING INFORMATION

Additional Supporting Information may be found online in the supporting information tab for this article.

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