



HHS Public Access

Author manuscript

J Pain Symptom Manage. Author manuscript; available in PMC 2019 April 01.

Published in final edited form as:

J Pain Symptom Manage. 2018 April ; 55(4): 1077–1084.e2. doi:10.1016/j.jpainsymman.2017.12.484.

Development and Assessment of a Measure of Parent and Child Needs in Pediatric Palliative Care

James P. Donnelly, PhD*,
Canisius College, Buffalo, NY, USA

Kim Downing, BSN, JD*,
Greater Illinois Pediatric Palliative Care Coalition, Chicago, IL, USA

Jason Cloen, LMSW,
CompassionNet, Rochester, NY, USA

Patricia Fragen,
Normal Moments, Naperville, IL, USA

Alyssa W. Gupton, LCSW,
CompassionNet, Rochester, NY, USA

Jen Misasi, CPNP, and
Greater Illinois Pediatric Palliative Care Coalition, Chicago, IL, USA

Kelly Michelson, MD, MPH
Northwestern University Feinberg School of Medicine and Ann & Robert H. Lurie Children's Hospital of Chicago, Chicago, IL USA

Abstract

Context—Pediatric palliative care has no evidence-based needs assessment measure. The Parent and Child Needs Survey (PCNeeds) is a new instrument designed to assess the needs of children in palliative care, including children receiving end-of-life care, and their families.

Objectives—This study examines the psychometrics of and respondents' perceptions about the PCNeeds.

Methods—Parents of children in four outpatient pediatric palliative care programs completed the PCNeeds and the World Health Organization Quality of Life-Brief tool (WHOQOL-BREF). Parents answered questions about demographics and the experience of completing the PCNeeds. Internal scale reliability was measured with Cronbach's alpha. Validity was assessed by correlating

Corresponding Author: Kelly Michelson, MD, MPH, 225 East Chicago Avenue, Box 73, Chicago, Illinois 60611-2605, Phone: 312-227-1606, Fax: 312-227-9675, k-michelson@northwestern.edu.

*James P. Donnelly and Kim Downing contributed equally to this work.

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Disclosures

We have no conflicts of interest to disclose.

the PCNeeds total and subscale scores with the WHOQOL-BREF subscales. Additional respondent perceptions were obtained via written comments and analyzed using content analysis.

Results—The 93 respondents were predominantly female ($n=69$, 74%); white ($n=79$, 85%); college graduates ($n=71$, 76%); and married or partnered ($n=75$, 81%). Internal reliability was acceptable (Cronbach's $\alpha=.83$), and validity correlations with the WHOQOL-BREF subscales were consistent with theoretical expectations (moderate negative correlations ranging from $-.36$ to $-.51$). The most frequently cited need not addressed by our survey was sibling impact ($n=17$, 18%). Twelve parents (13%) indicated that no content was missing. The least met needs were financial impact, family impact, and the child's physical problems besides pain. Sixty-eight percent of parents ($n=63$) rated completion of the survey as "easy" or "very easy."

Conclusion—Initial psychometric analysis of the PCNeeds is encouraging, but further study of reliability and validity with more diverse respondents is needed.

Keywords

Pediatric palliative care; Needs assessment; Hospice

Introduction

Pediatric palliative and hospice care (PPHC) seeks to deliver competent, compassionate, consistent care to children with chronic, complex, and/or life-threatening conditions and their families.¹ Despite advances in the field in recent years,^{2,3} studies indicate that a significant gap continues to exist between needs and services received by children in PPHC and their families.⁴⁻⁶

The diverse and multifaceted PPHC population has varying needs. Children with complex, chronic, and/or life-shortening conditions, have a constellation of medical problems including genetic or neuromuscular disorders and malignancies.^{1,7} Most require support from medical technology (e.g. a tracheostomy tube).⁷ Children enter PPHC programs at variable points in their illness, from diagnosis forward. The majority utilize PPHC for less than a year⁷ and have needs that fluctuate based on the child's health status as well as family composition, resources, and spiritual/cultural background. Unmet needs in PPHC include consistent communication, continuity of care, optimal symptom management, attention to family members, and access to bereavement support.^{6,8}

Needs assessment encompasses both quality of life and quality of care issues, making it an important measure for informing clinical practice.⁹ In adult palliative and hospice care, needs assessment tools exist for use in different settings and with different diseases (e.g. cancer, heart failure, dementia, in-patient, etc.).^{9,10} However, adult tools do not always translate easily to pediatric practice. PPHC is distinct from its adult counterpart because the diseases, psychosocial issues, and approaches to symptom relief and decision making are different. There are assessment methods, including proxy and patient reported outcome measures, that identify indicators of physical, emotional, or spiritual suffering in children.^{11,12} Unfortunately, instruments used in the assessment of typical children are not easily adapted for use with children with complex illnesses cared for under the umbrella of PPHC.

11,13–15 To date, no practice-derived, theory-based, empirically validated, comprehensive tool exists to assess the evolving needs of children receiving PPHC and their families.¹³

To address this void, we developed the Parent and Child Needs Survey (PCNeeds). PCNeeds incorporates issues specific to the pediatric palliative and hospice population, such as the parent-child relationship, the illness' impact on the family, and unique decision-making needs.^{1,16–20} The purpose of this study is to examine the psychometrics (reliability and validity) of and respondents' perceptions about the PCNeeds.

Methods

Study team and environment

The study team included professionals from academic institutions and community-based organizations and parent representatives. The community-based organizations included the Greater Illinois Pediatric Palliative Care Coalition (GIPPCC), a 501(c)(3) nonprofit organization seeking to improve access to quality, community-based PPHC in Illinois.²¹ Four community-based palliative care organizations participated: Horizon Hospice & Palliative Care (Chicago, Illinois), JourneyCare (Chicago, Illinois), Joliet Area Community Hospice (Joliet, Illinois), and CompassionNet (Rochester, New York). After completing data collection, Horizon Hospice & Palliative Care and JourneyCare merged into a single entity, JourneyCare. Other research team members were affiliated with two academic centers: Ann & Robert H. Lurie Children's Hospital of Chicago (Lurie Children's Hospital), Northwestern University Feinberg School of Medicine and Canisius College of Buffalo, New York. Parent representatives included three parents of children who had died and received community-based pediatric palliative care. One parent is also the founder of Normal Moments, a 501(c)(3) nonprofit organization that provides supportive services to families caring for children with life-limiting illnesses.

Development of PCNeeds

The PCNeeds was adapted (with permission) from the Needs at the End-of-Life Screening Tool (NEST), an instrument validated for adult palliative care populations.²² Development of the PCNeeds reflects input from existing literature about PPHC needs^{18–20} and expert input from a pediatric palliative care researcher, a research psychologist, GIPPCC members (hospital and community-based PPHC providers including physicians, nurses, expressive therapists, social workers, and chaplains), PPHC experts from the CompassionNet team (a social worker, nurse practitioner, and physician), bereavement specialists from Lurie Children's Hospital, and bereaved parents.

Initial satisfactory content validity (i.e., the point at which no further needs items were suggested and no further wording revisions were deemed necessary) for the PCNeeds was obtained via multiple cycles of review and discussion with the experts listed above. Content validity addresses the issue of how comprehensively and completely a measure captures the relevant aspects of the construct under study.²³ Content validity is strengthened by comprehensive literature searches, as well as input from experts. The care dimensions identified through literature review and input from experts in the field include: patient/

parent-clinician relationship, access to care, clinician communication, decision making, pain, physical symptoms other than pain, caregiving needs, life satisfaction/happiness, parent-child relationship, social connectedness, mental symptoms, personal acceptance/settledness, spirituality/religiousness, financial burden, and family-focused care.

Consisting of 22 items written at a 6th grade reading level, the PCNeeds is concise but comprehensive. Respondents rate their level of need on an 11 point scale ranging from minimum to maximum estimation of need. (See Appendix 1.) The PCNeeds was translated into Spanish by a certified translator.

Study design

This cross-sectional survey study of parents of PPHC patients was reviewed and approved by the Lurie Children's Hospital Institutional Review Board. Eligible participants included English or Spanish speaking parents or legal guardians (hereafter 'parents') of a child who had been enrolled in one of the four participating community-based PPHC organizations for at least three weeks.

Study team members requested participation from eligible parents. Parents were verbally provided with study details and had the opportunity to discuss their rights and ask about any aspect of the study. Although parents were not asked to provide written consent, they were given printed information about the study which included all elements of informed consent and the statement, "By completing the survey you are agreeing to participate in this study." Participants could complete either a hard-copy or an online version of the anonymous survey. Completed hard-copy surveys were mailed directly to the Lurie Children's Hospital study team. Up to three phone calls were made to parents reminding them to complete the survey. The PPHC organizations collected basic information from patient charts about date of admission to the program, diagnoses, date of birth, and race/ethnicity. Patient diagnoses were placed into categories developed by group consensus (involving three co-authors) and based on previous definitions for children with complex chronic conditions.^{24,25}

A power analysis was conducted using Stata 14 to estimate the target sample size. To identify a minimum correlation of .30 with power of .80 and an alpha error rate of .05, the target sample size was estimated at 85 participants. There is no minimum cut-off when examining correlations in an analysis of construct validity, which means that measure developers must identify a minimum correlation. In this study, a correlation of .30 was considered the smallest correlation that would provide meaningful evidence of convergent validity with scores on the World Health Organization Quality of Life-Brief tool (WHOQOL-BREF), the established measure utilized in this study.^{23,26} A correlation of .30 is considered a medium effect.²⁷

Questionnaire content

The study questionnaire had four parts. Part I was the PCNeeds, with a space after each item for parents to provide comment. To check for comprehensiveness, the PCNeeds was followed by an open-ended item asking about additional needs not addressed. Part 2 was the WHOQOL-BREF, which measures four domains: Physical Health, Psychological Health, Social Relationships, and Environment. The WHOQOL-BREF was chosen because of its

anticipated relationship with needs and its well-established psychometric properties.²⁸ The estimated Cronbach α for the WHOQOL-BREF domains are: Physical Health .82, Psychological Health .81, Environment .80, and Social Relationships .68.²⁸ All four domains demonstrated discriminant validity when responses from sick and well populations were compared,²⁸ and construct validity was shown by correlating domain scores with a general overall quality of life item.²⁸ Part 3 inquired about demographic information, and part 4 asked respondents how long it took to finish the survey and how easy/difficult it was to complete (with five response options ranging from "very easy" to "very hard").

Data analysis

Data analysis included an examination of data quality (accuracy and missing data), item and scale psychometrics, and content analysis of qualitative data.

Questionable and missing survey values were compared with the original returned survey and replaced as needed to accurately capture responses. There was no imputation of missing values because most respondents provided relatively complete data. Five online surveys received were not included in the analysis because they contained >50% missing responses.

The analysis used standard methods to assess the measure's psychometric quality.^{23,26} This included analysis of the individual items and the complete scale, and an exploratory analysis of three potential subscales. The item analysis examined score distributions (range, variance, skewness, kurtosis), central tendency (means, medians), and correlations. Internal consistency reliability of the measure was estimated with Cronbach's alpha. A p -value of $<.05$ was considered statistically significant. Statistical analyses were conducted with SPSS 23 and Stata 14.

Construct validity was assessed via correlations with the WHOQOL-BREF, an established measure of a related construct. We hypothesized that the PCNeeds scores would negatively correlate with the WHOQOL-BREF subscales (i.e., greater unmet needs would be associated with poorer quality of life ratings). Validity correlations between the PCNeeds scores and the WHOQOL-BREF subscales were examined. The PCNeeds total score was obtained by reverse scoring eleven of the PCNeeds items so higher scores would indicate a greater level of need and then summing all items.

Exploratory analysis of three theoretically based subscales was conducted. Subscale constructs and candidate items (sets of items thought to represent similar needs) were identified by three co-authors independently and then reviewed for consensus. This discussion involved comparing the items in each group as well as the construct that each group seemed to represent. Three potential subscales were identified: Care Team Interactions (items 1–5, 17, 18, and 22), Patient Symptom Management (items 6–10), and Parent-Family Impact (items 11–16 and 19–21). The subscale inter-correlations were examined, resulting in exclusion of item 5 (degree of inclusion in medical decisions) because it was not correlated with any other item in the Care Team Interactions subscale set. The subscales were scored by summing and then dividing by the number of items in the scale so that all would be scaled as 0–10, with 10 indicating the greatest level of need. The subscale psychometric characteristics were examined in the same manner as the total score.

Using content analysis,²⁹ we analyzed the comments following each PCNeeds item and responses to the question, “What other challenges do you, your child or your family face that we have not asked about in the survey?” One study team member created preliminary codes based on the content. A second study team member reviewed the preliminary codes, making additions and modifications. The two reviewers developed a final coding list that included only codes pertaining to the PCNeeds. One study team member used this final coding list to code the entire data set. The second study team member reviewed that analysis, and discrepancies were resolved by consensus.

Results

Parent and patient characteristics

Ninety-three parents returned a hard-copy of the survey. Five parents partially completed the online survey, but these incomplete surveys are not included in the results below because the majority of responses were missing. Table 1 presents participant demographics. The respondents were mostly biological parents of children with non-malignant conditions, mothers, well-educated, married, and white. No Spanish speaking parents participated. Fifty-three (57%) of parents lived in New York, and 40 (43%) in Illinois. In 81 cases (87%), one parent from a family provided data. For six families, two parents completed a survey ($n=12$, 13%).

Item analysis

Table 2 presents each item’s central tendency (mean, median), variability (standard deviation, minimum/maximum), and degree of missing data. Except for the first two items, which related to the palliative care team’s communication of respect for the patient and parent, most of the scale range was utilized for each item. The PCNeeds total scores were normally distributed (skewness=.029, kurtosis=-.531), with a mean of 79.29 ($SD=26.44$).

The missing data column in Table 2 shows that 19 of the 22 items had five or fewer missing responses, 14 had two or fewer missing, and 6 had no missing responses. Three items showed less complete data. The first, item 18, asked about confidence in meeting care goals in the final stages of life (missing=14, 12%). Comments from those who left this item blank included four who wrote “don’t know”, two who said “can’t think about it”, and two who commented “NA”. For item 5, which pertained to involvement in medical decisions, there was no numerical response on ten surveys (11%), of which six included positive statements in the comment area for this item. There were nine (10%) missing responses to item 19, regarding satisfaction with religious and/or spiritual support. For this item, two parents commented “not religious” and two wrote “NA”.

Reliability

Cronbach’s coefficient alpha was .83 for the set of 22 items. When the twelve non-independent cases (i.e., the six families that had two parents respond) were excluded, alpha was .84. Twenty items had an item-total correlation of at least $r=.30$, suggesting that nearly all of the individual items were consistent contributors to total score variance. The two exceptions were items 4 and 5, on understanding medical information ($r=-.04$) and desire

for greater involvement in medical decisions ($r=.10$). The highest item-total correlation was item 9, which asked about the difficulty of managing the child's emotional needs ($r=.68$).

Validity

Intra-class correlations (ICCs) were calculated for the PCNeeds total, subscales, and the four WHOQOL-BREF scales to estimate the amount of variance due to family membership (in six families, two parents returned a survey). All ICCs were less than .05 except for the WHOQOL-BREF Environment scale, which was .23, indicating that 23% of this scale's variance was due to family membership. We therefore decided to drop the Environment scale from the validity analysis.

Table 3 presents correlations between the PCNeeds total score and the three WHOQOL-BREF subscales, along with scale means and standard deviations. Negative correlations were found between the PCNeeds total score and all of the quality of life (QoL) subscales, ranging from $-.36$ for the Physical Health subscale to $-.51$ for the Social Relationships subscale. Scatterplots of the PCNeeds-QoL correlations confirmed linear relationships in each case (data not shown). The inter-correlations of the WHOQOL-BREF subscales were all significant, positive, and ranged from .33 (Physical Health-Social Relationships, $p<.01$) to .48 (Physical Health-Psychological Health, $p<.001$).

PCNeeds subscales

The exploratory PCNeeds subscale analysis revealed that the Patient Symptom Management subscale had the highest need level ($M=4.98$, $SD=2.31$), followed by Parent-Family Impact ($M=2.75$, $SD=5.33$) and Care Team Interactions ($M=1.26$, $SD=1.05$). All three subscales had roughly normal distributions, with some skew noted in the Care Team Interactions data (in the direction of lower needs, primarily due to the consistently positive ratings given to care team respect for patient and parent). Cronbach's alpha was .65 for the Care Team Interactions subscale, .77 for the Patient Symptom Management subscale, and .75 for the Parent-Family Impact subscale.

Correlations between the PCNeeds subscales and the WHOQOL-BREF subscales showed a pattern similar to the relationship between the PCNeeds total score and the WHOQOL-BREF subscales (Table 3), with low to moderate negative correlations for all bivariate pairs (6/12 correlations were greater than $-.30$). The strongest correlation was between the WHOQOL-BREF Psychological Health scale and the PCNeeds Parent-Family Impact scale ($r=-.56$, $p<.001$). The weakest correlation was between the WHOQOL-BREF Psychological Health scale and the Care Team Interactions score ($r=-.18$, $p>.05$).

Qualitative analysis

Parents left no comments related to item content or wording for seven of the PCNeeds items (item 2, 3, 12 – 15, and 22). The items with the most comments were 5 ($n=14$), 6 ($n=15$), 18 ($n=9$), and 19 ($n=8$). After item 5, eight parents made comments that did not match their numeric response, four wrote "NA", and two did not mark a score but responded to the question in their comment. After item 6, eleven parents indicated that they didn't know the answer, two parents made word choice suggestions, and two parents did not mark a score but

responded to the item in their comment. After item 18, five parents indicated that they didn't know the answer, two wrote "NA", and two indicated that they couldn't think about it. After item 19, four parents indicated they were not religious and four wrote "NA".

Sixty-nine parents (74%) responded to the question "What other challenges do you, your child or your family face that we have not asked about in the [PCNeeds] survey?" Twelve parents (13%) indicated that there was nothing to add, and nine (10%) included a comment considered nonreactive to the posed question. Seventeen parents (18%) noted challenges faced by the patient's sibling(s). Other unaddressed challenges included: family issues and the impact on work (each $n=6$, 6%), lack of respite care and not having the appropriate physical space to care for the patient (each $n=5$, 5%), and issues with spouses, finances, and obtaining adequate care in the home (each $n=4$, 4%). Other challenges were mentioned by less than 3 parents.

Respondent burden

Most respondents rated the survey as "very easy" or "easy" ($n=63$, 68%), with 23 (25%) rating it as "neither easy nor hard" and seven (8%) considering it "very hard". Parent report of time estimates for completed the survey were: "Less than five minutes" ($n=8$, 9%), "5–15 minutes" ($n=60$, 65%), "15–30 minutes" ($n=20$, 22%), and "More than 30 minutes" ($n=4$, 4%).

Discussion

The concept of needs is fundamental in PPHC,^{4,5,30} but there has not been a specific measure assessing the needs of children in PPHC and their families. This study provides initial reliability and validity data about a measure of child and family needs in PPHC that could fill this gap.²³

The PCNeeds scale demonstrates good reliability and validity. The internal reliability estimate of .83 indicates a high level of consistency within the scale. The correlation coefficients with the WHOQOL-BREF are also encouraging.²⁶ Theoretically, higher unmet needs suggest lower quality of life, and the moderate negative correlations of the PCNeeds total score with the WHOQOL-BREF subscales accord with this theory.

From a psychometric perspective, the limited range of items 1 and 2 (care team respect for the patient and family) are concerning. However, this concern is balanced by reliability and validity coefficients that indicate good overall scale performance. Since care team respect is a fundamental PPHC need, here content validity may supersede the statistical evidence typically required to establish criterion-related validity. Future studies with different samples might produce greater variability on these items.

The PCNeeds content addresses core PPHC challenges, such as symptom management, communication, and financial and emotional impact. Given its relevant content and promising psychometrics, the PCNeeds has multiple potential applications including individual assessment, program evaluation, and research.³¹ The scale could help clinicians quantitatively gauge family and patient unmet needs, informing treatment planning

conversations from PPHC enrollment to discharge. For example, the total score could serve as a baseline and the highest rated needs could direct treatment plans. The PCNeeds might also help families articulate concerns in concrete terms, supporting an “unfolding” kind of communication²² in which the items focus discussion and perhaps trigger engagement with new services. Program managers and clinicians could use results about met and unmet needs to develop new programs or consider issues of resource allocation. Identification of child and family needs could also serve as an indicator of program quality. Finally, as PPHC becomes increasingly evidence-based, the PCNeeds may be a relevant outcome measure in quasi-experimental and experimental research.

The PCNeeds was developed with thorough consideration of content validity. However, qualitative data from participants’ comments suggest adding items assessing the needs of siblings and the parents’ relationship. We plan to add items reflecting these issues to future versions of the PCNeeds.

We acknowledge some study limitations. Participants were mainly well-educated, white, and female, and all were English speaking, potentially limiting the generalizability of the results. Potential differences based on patient age, diagnosis, or other subgroups were not assessed. This study only examined the PCNeeds parent version; a patient version exists but requires additional study. Furthermore, responses suggest high levels of satisfaction in many areas, for example, the palliative care team’s communication and respect for the patient and parent. Having a sample of parents with more diverse opinions of their PPHC providers might have altered the scale’s psychometrics and the endorsement levels of individual items. In addition, few participants adequately completed the online version of the survey. This may reflect the fact that parents had to type in the exact website address themselves and complete the online survey on a home computer or other personal device. Follow-up studies could enhance online participation by providing a tablet version for completion during a home, clinic, or hospital visit. Finally, although the three PCNeeds subscales showed acceptable psychometrics, additional study is required to establish a stronger level of confidence before recommending usage.

In conclusion, the PCNeeds shows promising psychometrics and could be a useful tool in individual assessment, program evaluation, and as a PPHC research outcome measure. Additional research should engage more diverse parent and patient populations, assess the PCNeeds patient version, and test items related to the needs of siblings and the parents’ relationship.

Acknowledgments

Research reported in this publication was supported, in part, by the National Institutes of Health’s National Center for Advancing Translational Sciences, Grant Number UL1TR000150. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. This work was also supported by a grant from the Northwestern University Alliance for Research in Chicagoland Communities. We would like to thank Margaret Rudnik, MBA, from the Greater Illinois Pediatric Palliative Care Coalition, Elizabeth and Michael Terhorst, and the Horizon Hospice & Palliative Care, JourneyCare, Joliet Area Community Hospice, and CompassionNet teams for their contributions to the development of the PCNeeds scale and the design and implementation of this study. We would also like to thank all the parents who participated in this study for their time and thoughtful contributions.

References

1. Friebert S, Williams C. [Accessed September 19, 2017] NHPCO's Facts and Figures Pediatric Palliative and Hospice Care in America. 2014. Available from: https://www.nhpco.org/sites/default/files/public/quality/Pediatric_Facts-Figures.pdf
2. Groh G, Borasio GD, Nickolay C, Bender HU, von Luttichau I, Fuhrer M. Specialized pediatric palliative home care: a prospective evaluation. *J Palliat Med.* 2013; 16:1588–1594. [PubMed: 24168349]
3. Hays RM, Valentine J, Haynes G, et al. The Seattle Pediatric Palliative Care Project: effects on family satisfaction and health-related quality of life. *J Palliat Med.* 2006; 9:716–728. [PubMed: 16752977]
4. Liben S, Papadatou D, Wolfe J. Paediatric palliative care: challenges and emerging ideas. *Lancet.* 2008; 371:852–864. [PubMed: 17707080]
5. Himelstein BP, Hilden JM, Boldt AM, Weissman D. Pediatric palliative care. *N Engl J Med.* 2004; 350:1752–1762. [PubMed: 15103002]
6. Contro N, Larson J, Scofield S, Sourkes B, Cohen H. Family perspectives on the quality of pediatric palliative care. *Arch Pediatr Adolesc Med.* 2002; 156:14–19. [PubMed: 11772185]
7. Feudtner C, Kang TI, Hexem KR, et al. Pediatric palliative care patients: a prospective multicenter cohort study. *Pediatrics.* 2011; 127:1094–1101. [PubMed: 21555495]
8. van der Geest IM, Darlington AS, Streng IC, Michiels EM, Pieters R, van den Heuvel-Eibrink MM. Parents' experiences of pediatric palliative care and the impact on long-term parental grief. *J Pain Symptom Manage.* 2014; 47:1043–1053. [PubMed: 24120185]
9. Girgis A, Waller A. Palliative care needs assessment tools. In: Cherny N, Fallon M, Kaasa S, Portenoy RK, Currow DC, editors *Oxford Textbook of Palliative Medicine*. Fifth. Oxford: Oxford University Press; 2015.
10. Antunes B, Harding R, Higginson IJ. Euroimpact. Implementing patient-reported outcome measures in palliative care clinical practice: a systematic review of facilitators and barriers. *Palliat Med.* 2014; 28:158–175. [PubMed: 23801463]
11. Emanuel LL, Powell RA, Handzo G, Michelson KN, Dhingra L. Validated assessment tools for psychological, spiritual, and family issues. In: Cherny N, Fallon M, Kaasa S, Portenoy RK, Currow DC, editors *Oxford Textbook of Palliative Medicine*. Fifth. Oxford: Oxford University Press; 2015.
12. Wolfe J, Orellana L, Cook EF, et al. Improving the care of children with advanced cancer by using an electronic patient-reported feedback intervention: results from the PediQUEST randomized controlled trial. *J Clin Oncol.* 2014; 32:1119–1126. [PubMed: 24616307]
13. Harding R, Wolfe J, Baker JN. Outcome Measurement for Children and Young People. *J Palliat Med.* 2017; 20:313. [PubMed: 28072920]
14. Huang IC, Shenkman EA, Madden VL, Vadaparampil S, Quinn G, Knapp CA. Measuring quality of life in pediatric palliative care: challenges and potential solutions. *Palliat Med.* 2010; 24:175–182. [PubMed: 20007819]
15. Ahmed N, Hughes P, Winslow M, Bath PA, Collins K, Noble B. A Pilot Randomized Controlled Trial of a Holistic Needs Assessment Questionnaire in a Supportive and Palliative Care Service. *J Pain Symptom Manage.* 2015; 50:587–598. [PubMed: 26087472]
16. Baker JN, Levine DR, Hinds PS, et al. Research Priorities in Pediatric Palliative Care. *J Pediatr.* 2015; 167:467–470 e463. [PubMed: 26028284]
17. Jones BL, Contro N, Koch KD. The duty of the physician to care for the family in pediatric palliative care: context, communication, and caring. *Pediatrics.* 2014; 133:S8–15. [PubMed: 24488541]
18. Donnelly JP, Huff SM, Lindsey ML, McMahon KA, Schumacher JD. The needs of children with life-limiting conditions: a healthcare-provider-based model. *Am J Hosp Palliat Care.* 2005; 22:259–267. [PubMed: 16082911]
19. Mularski RA, Curtis JR, Billings JA, et al. Proposed quality measures for palliative care in the critically ill: a consensus from the Robert Wood Johnson Foundation Critical Care Workgroup. *Crit Care Med.* 2006; 34:S404–411. [PubMed: 17057606]

20. Dokken DL, Heller KS, Levetown M. , et al. [Accessed June 22, 2017] Quality domains, goals, and indicators of family-centered care of children living with life-threatening conditions. 2001. Rev'd 2002. Available from <http://www.ippcweb.org/quality.htm#quality>

21. [Accessed February 2, 2017] The Greater Illinois Pediatric Palliative Care Coalition. Available from: <http://www.gippcc.org/index.html>

22. Emanuel LL, Alpert HR, Emanuel EE. Concise screening questions for clinical assessments of terminal care: the needs near the end-of-life care screening tool. *J Palliat Med.* 2001; 4:465–474. [PubMed: 11798478]

23. Trochim WM, Donnelly JP, Arora K. *The Essential Research Methods Knowledge Base.* Boston, MA: Cengage; 2016.

24. Feudtner C, Hays RM, Haynes G, Geyer JR, Neff JM, Koepsell TD. Deaths attributed to pediatric complex chronic conditions: national trends and implications for supportive care services. *Pediatrics.* 2001; 107:E99. [PubMed: 11389297]

25. Feudtner C, Feinstein JA, Zhong W, Hall M, Dai D. Pediatric complex chronic conditions classification system version 2: updated for ICD-10 and complex medical technology dependence and transplantation. *BMC pediatrics.* 2014; 14:199. [PubMed: 25102958]

26. DeVellis RF. *Theory and Applications.* 2. Thousand Oaks, CA: Sage Publications; 2003. Scale Development.

27. Cohen J. *Statistical Power Analysis for the Behavioral Sciences (2nd Edition).* 2. Mahwah, NJ: Erlbaum; 1988.

28. Skevington SM, Lotfy M, O'Connell KA, Group W. The World Health Organization's WHOQOL-BREF quality of life assessment: psychometric properties and results of the international field trial. A report from the WHOQOL group. *Qual Life Res.* 2004; 13:299–310. [PubMed: 15085902]

29. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qualitative health research.* 2005; 15:1277–1288. [PubMed: 16204405]

30. Pizzo PA. Thoughts about Dying in America: Enhancing the impact of one's life journey and legacy by also planning for the end of life. *Proceedings of the National Academy of Sciences of the United States of America.* 2016; 113:12908–12912. [PubMed: 27830645]

31. Altschuld JW, Witkin BR. *From needs assessment to action.* Thousand Oaks, CA: Sage; 2000.

Appendix 1

Pediatric Palliative Care - Parent & Child Needs Survey

Introduction

- The following questions will help us understand the challenges that you, your child and your family CURRENTLY face.

Directions

- Please circle the number (using the scale from 0 to 10) that best answers each question.
- If you would like to include additional information, please write in comments after the question.

Questions

1. How much do you feel your care team respects your child?

0 1 2 3 4 5 6 7 8 9 10

Not at all

Completely

2. How much do you feel your care team respects you?

0 1 2 3 4 5 6 7 8 9 10

Not at all

Completely

Pediatric Palliative Care - Parent & Child Needs Survey	
3. How difficult is it to get your child the medical care he/she needs?	
0 1 2 3 4 5 6 7 8 9 10	
Not at all	Extremely
Difficult	Difficult
4. How well do you understand the medical information about your child's illness?	
0 1 2 3 4 5 6 7 8 9 10	
Not at all	Completely
5. How much do you want to be <i>more</i> included in medical decisions about your child?	
0 1 2 3 4 5 6 7 8 9 10	
Not at all	A great deal
6. How often does your child have pain?	
0 1 2 3 4 5 6 7 8 9 10	
Never	All the time
7. How much does your child have other physical problems besides pain?	
0 1 2 3 4 5 6 7 8 9 10	
Not at all	A great deal
8. How difficult is it to take care of your child's physical needs?	
0 1 2 3 4 5 6 7 8 9 10	
Not at all	Extremely
Difficult	Difficult
9. How difficult is it to take care of your child's emotional needs?	
0 1 2 3 4 5 6 7 8 9 10	
Not at all	Extremely
Difficult	Difficult
10. How much is your child able to participate in activities that he/she enjoys?	
0 1 2 3 4 5 6 7 8 9 10	
Not at all	A great deal
11. How much are you able to participate in activities that you enjoy?	
0 1 2 3 4 5 6 7 8 9 10	
Not at all	A great deal
12. How satisfied are you with your relationship with your child?	
0 1 2 3 4 5 6 7 8 9 10	
Not at all	Completely
13. How often do you talk to someone about your child's situation?	
0 1 2 3 4 5 6 7 8 9 10	
Never	Anytime I want
14. How often do you feel anxious?	
0 1 2 3 4 5 6 7 8 9 10	
Never	Always
15. How often do you feel depressed?	
0 1 2 3 4 5 6 7 8 9 10	
Never	Always

Pediatric Palliative Care - Parent & Child Needs Survey

16. How often do you think about your child dying?

0 1 2 3 4 5 6 7 8 9 10

Never Always

17. If your child's condition gets worse, how confident are you that your care goals for your child would be achieved by their healthcare team?

0 1 2 3 4 5 6 7 8 9 10

Not at all Completely

18. During the final stages of your child's life, how confident are you that your care goals for your child will be achieved by the healthcare team?

0 1 2 3 4 5 6 7 8 9 10

Not at all Completely

19. How satisfied are you with your religious or spiritual support?

0 1 2 3 4 5 6 7 8 9 10

Not at all Completely

20. How much of a financial hardship is your child's illness for you?

0 1 2 3 4 5 6 7 8 9 10

None A great deal

21. How often do you think about the impact of your child's illness on your family?

0 1 2 3 4 5 6 7 8 9 10

Never Always

22. Overall, how much do you feel that you are getting what you need from the care team?

0 1 2 3 4 5 6 7 8 9 10

Not at all Completely

Table 1

Participant Characteristics (N=93)

Parent Status	
Biological parent	86 (92%)
Adoptive parent	6 (7%)
Foster parent	1 (1%)
Gender	
Female	69 (78%)
Male	20 (23%)
Unknown	4 (4%)
Patient Diagnosis	
Cancer	16 (20%)
Cancer/blood	1 (1%)
Cardiac	4 (5%)
Chromosomal Abnormality	7 (9%)
GI	2 (3%)
Kidney	1 (1%)
Metabolic	4 (5%)
Metabolic/neurologic	3 (4%)
Neuro	36 (46%)
Respiratory	5 (6%)
Unknown	14 (15%)
Race/Ethnicity	
Asian	1 (1%)
African-American	7 (8%)
Hawaiian	1 (1%)
White	79 (85%)
Other	4 (4%)
Parent Education	
High school	17 (18%)
College or beyond	71 (78%)
Other	5 (5%)
Parent Marital Status	
Divorced	5 (5%)
Living as married	4 (4%)
Separated	5 (5%)
Married	71 (77%)
Single	4 (4%)
Widowed	3 (3%)
Unknown	1 (1%)

Table 2

Item Descriptive Statistics (N=93)

Item ^a	<i>M</i> (<i>SD</i>)	<i>Mdn</i>	<i>Min/Max</i>	<i>n</i> (%) <i>Missing</i>
1. Respect: child ^b	.33 (.81)	0	0/4	0 (0)
2. Respect: parent ^b	.43 (.88)	0	0/4	0 (0)
3. Difficulty getting care	2.87 (3.18)	2	0/10	0 (0)
4. Medical information ^b	1.29 (1.50)	1	0/8	0 (0)
5. Included in med decisions	6.05 (4.13)	7	0/10	10 (10.6)
6. How often pain	4.08 (2.51)	4	0/10	5 (5.4)
7. Phys problems (not pain)	6.84 (3.17)	8	0/10	4 (4.3)
8. Child physical needs	5.55 (3.14)	6	0/10	2 (2.2)
9. Child emotional needs	4.20 (3.55)	3	0/10	4 (4.3)
10. Child enjoyable activities ^b	5.02 (3.17)	5	0/10	5 (5.4)
11. Parent enjoyable activities ^b	5.81 (2.54)	7	0/10	4 (4.3)
12. Relationship w/child ^b	1.02 (1.54)	0	0/7	1 (1.1)
13. Talk to someone ^b	2.36 (2.68)	1.5	0/9	1 (1.1)
14. Anxious	5.90 (2.46)	6	0/10	1 (1.1)
15. Depressed	4.29 (2.71)	5	0/9	0 (0)
16. Think about child dying	5.79 (2.87)	6	0/10	1 (1.1)
17. Confidence re: care goals ^b	1.52 (1.79)	1	0/8	2 (2.2)
18. Final stages care goals ^b	1.50 (1.95)	1	0/8	14 (12.3)
19. Religious/spiritual support ^b	2.06 (2.68)	1	0/10	9 (9.7)
20. Financial hardship	6.26 (2.99)	7	0/10	1 (1.1)
21. Impact on family	7.79 (2.48)	2	0/10	2 (2.2)
22. Overall needs met ^b	1.15 (1.32)	1	0/6	0 (0)

^aPlease see appendix for full wording of each item.

^bItem reversed so that higher number indicates greater need.

Abbreviations: M, mean; SD, standard deviation; Mdn, median; Min, minimum; Max, maximum

Table 3

Correlations, Means, and Standard Deviations for Scores on Needs Total and the WHOQOL Subscales

Measure	1	2	3	4
1. PCNeeds Total	--	-.36 ^a	-.49 ^a	-.51 ^a
2. Physical		--	.48 ^a	.33 ^a
3. Psychological			--	.45 ^a
4. Social Relations				--
<i>M</i>	79.29	51.68	60.71	58.24
<i>SD</i>	26.44	14.52	13.02	22.01

^a*p*<.01

Abbreviations: M, mean; SD, standard deviation

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript