

# Patient-reported Outcomes in End-of-Life Research in Pediatric Oncology

Pamela S. Hinds,<sup>1,4</sup> PhD, RN, FAAN, Jennifer Brandon,<sup>1</sup> Caitlin Allen,<sup>1,4</sup> PhD, Nobuko Hijiya,<sup>2,4</sup> MD, Rachel Newsome,<sup>3,4</sup> RN, BSN, and Javier R. Kane,<sup>2,4</sup> MD

<sup>1</sup>Division of Nursing Research, <sup>2</sup>Department of Oncology, <sup>3</sup>Patient Care Services, and <sup>4</sup>St. Jude Palliative and End-of-Life Care Task Force at St. Jude Children's Research Hospital, Memphis, TN 38105, USA

**Objective** The purpose of this review of published literature was to identify the number and focus of empirically based papers that included research methods used to directly solicit patient-reported outcomes (PRO) from pediatric oncology patients at end of life. **Methods** Key terms including “pediatric or child and oncology or cancer and end of life or palliative or hospice or dying” were used with five data bases (PubMed, Ovid, Cochrane, PsycInfo & PsycArticles, and CINAHL) for English language literature published between January, 2001 and June, 2006. All retrieved documents were independently reviewed by a panel of six (nurses, physicians, and one psychologist) with backgrounds in pediatric oncology. **Results** Thirty-five publications were identified but nine (25.7%) were eliminated from the analysis as they did not meet inclusion criteria. Of the remaining 26, four (15.4%) included patient-reported outcomes, six (23.1%) included parent only-reported outcomes, and five (19.2%) included staff only-reported outcomes. Nine (34.6%) were retrospective medical record reviews. Two (7.7%) included parent and record review data or parent and physician reports. **Conclusions** Empirically-based end-of-life publications in pediatric oncology are relatively few in number and nearly 85% of completed studies do not include PRO.

**Key words** end of life; literature review; patient-reported outcomes; pediatric oncology.

Patient-reported outcomes (PRO) are defined as a “measurement of any aspect of patient’s health status that comes directly from the patient (i.e., without the interpretation of the patient’s responses by physician or others)” (Office of New Drugs and the Office of Medical Policy, 2006). Soliciting PRO in pediatric oncology clinical trials or descriptive studies could provide clinically valuable information about the patient’s treatment or disease-related experiences including symptoms and toxicities and could yield information about the burden and benefits of participating in certain treatments or behavioral interventions. In the past decade, PRO have had what is described as a significant role in the approval of new medicines by the Federal Drug Agency (Willke, Burke, & Erickson, 2004). An additional and particularly satisfying benefit for health care providers is to guide or direct the treatments and their care of children and adolescents at end of life by the goals and priorities

reported by these patients. To maximize such benefits, reliable and valid instruments for use in clinical care contexts need to be available, evaluated for their sensitivity, used appropriately with the specified pediatric participants in terms of their development, cognitive abilities, culture and linguistic backgrounds, and their clinical context. The use of PRO is increasing in oncology with one notable exception: in pediatric oncology at end of life (Lorenz et al., 2006). The purpose of this article is to review the current status of the use of PRO with children and adolescents with cancer who are at end of life.

## Methods

Key terms including “pediatric or child *and* oncology or cancer *and* end of life or palliative or hospice or dying” were used with five data bases (PubMed, Ovid, Cochrane,

All correspondence concerning this article should be addressed to Pamela S. Hinds, PhD, RN, FAAN, 332 N. Lauderdale, Memphis, TN 38105-2719. E-mail: pam.hinds@stjude.org.

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PsycInfo & PsycArticles, and CINAHL) for English language literature published between January, 2001 and June, 2006. Inclusion criteria included (a) research or project methods explicitly described, (b) data presented in a way that made it possible to accurately identify the data from the pediatric oncology participants, and (c) no duplicative data in two or more publications. A panel of six reviewers (three with nursing backgrounds, two physicians, and one psychologist) with pediatric oncology experience independently reviewed all 35 publications. Each completed a review form rating each of the publications on the three inclusion criteria. Panelists then categorized the publications that met all inclusion criteria by type of report: patient-report (any publication that included PRO including reports that also contained other forms of reports such as parent or medical record), parent-only report, staff-only report, medical record reviews, and others (any publication that included combined reports from parents, records and/or staff). Rater agreement was assessed by publication, category of publication, and by total group of publications. Rater agreement for each inclusion criterion and for category of report type included: explicit methods, 96.9% agreement; able to identify data specific to pediatric oncology patients, 94.4% agreement; no duplicative data, 95.7% agreement; and category type, 96.9% agreement.

## Results

Thirty-five publications were identified and of these, nine (25.7%) were deemed ineligible: one was a population-based report in which the three age categories included in the data analysis plan were ages 1–64, 65–79, and 80 years and older (Van den Block et al., 2006) and thus it was not possible to determine which findings were derived from the pediatric age group; one described the creation of a hospital-based quality-improvement rapid response program to address rapidly escalating pain, dyspnea or agitation (Houlahan, Branowicki, Mack, Dinning, & McCabe, 2006); one described the importance of implementing pediatric palliative care for children with life-threatening illnesses at diagnosis (Mack & Wolfe, 2006); one was a report of parent proxy ratings of their child's quality of life at end of life as well as their satisfaction with a palliative care program (Hays et al., 2006) and two others involved patient-reported symptom experiences (Siden & Nalewajek, 2003) or nurse and record reports on symptoms of dying children (Drake, Frost, & Collins, 2003), but the findings specific to pediatric oncology participants could

not be distinguished from those of other nononcology related participants; one that included patient and parent interview comments but as vehicles for clinician perspectives on end-of-life care (Hurwitz, Duncan, & Wolfe, 2004); and the remaining two excluded publications were described as a "poignant interview" with two different women who had experienced the death of a child (Berg & Ahmann, 2006; Dokken & Ahmann, 2006) but published without methods being described and without an analysis.

Of the twenty-six remaining publications, only four (15.4%) included PRO. None of the four *only* included PRO; one included patient ( $n=3$ ) and parent ( $n=9$ ) reports regarding the impact of the cancer and its treatment on their daily lives, and family communication about the cancer progressing and about enrollment on a Phase 1 trial (Barrera, D'Agostino, Gammon, Spencer, & Baruchel, 2005); one included patient pain reports and medical record review data on pain relief medications (Caran, Dias, Seber, & Petrilli, 2005); one included a combination of patient or family and nurse reports to identify the presence and impact of symptoms and to identify those most difficult to treat in patients with progressive disease (Goldman, Hewitt, Collins, Childs, & Hain, 2006), and the final publication included patient-, parent-, and physician reports plus medical record review data regarding end-of-life decision making related to do not resuscitate orders, enrollment in a Phase 1 trial when the three groups agreed that no curative options remained, or terminal care (Hinds et al., 2005). These reports were all published in the preceding 3 years and involved settings from five different countries: Brazil, Canada, the United Kingdom, Australia, and the United States. The purpose of each reported study and the focus of each study differed as did the ages of the patients involved and the research methods (Table 1). One report used the institution's clinical pain report as the PRO (Caran et al., 2005), one relied upon a questionnaire constructed for use in the study (Goldman et al., 2006), and two relied upon open-ended interview questions that were derived from specified theoretical perspectives (Barrera et al., 2005; Hinds et al., 2005). None included previously validated instruments used in pediatric or pediatric oncology patient groups. The diverse foci and methods make a review of the strength of the evidence in any topical area too preliminary at this time.

The limited number of PRO in end-of-life pediatric oncology publications is placed into a context by reviewing the remaining 22 publications that met the inclusion criteria. The largest category ( $n=9$  publications) was that

**Table I.** Patient-Reported Outcomes

Author	Study purpose	Sample	Design	Patient report/methods	Parent report/methods	Staff report/methods
Barrera, et al. (2005)	To investigate health-related quality of life in children with incurable cancer eligible for Phase 1 trials and the reasons why families consider participating	Three children and nine parents	Prospective interview, single institution	Semi-structured interview	Semi-structured interview	None
Caran et al. (2005)	To characterize the clinical aspects and treatment of mild to severe pain in Brazilian children and adolescents with cancer	184 pain episodes involving 135 patients	Prospective, nonrandomized, single institution	Pain was classified by its cause, physiopathology, and intensity; treatment based on the WHO guidelines was administered and evaluated	In cooperation with a nurse or family member the child gave pain estimates using age-specific face or numerical pain scales	None
Goldman, et.al. (2006)	To survey symptoms in children/young people with progressive cancer and identify which are the most important and which are the most difficult to treat effectively	185 palliative care patients	Prospective survey, 22 participating sites	When possible, symptom data collected from the child	When necessary, the parent completed the symptom checklist	Two surveys completed by the key health professional coordinating palliative care for the child in collaboration with the child and family
Hinds et al. (2005)	To identify the end-of-life care preferences of pediatric oncology patients and the factors influencing their decisions	Twenty pediatric oncology patients	prospective study, two-site study	Interviewed with open-ended questions	Interviewed with open-ended questions	Interviewed with open-ended questions

**Table II.** Medical Record Review

Author	Study purpose	Sample	Design
Bradshaw et al. (2005)	To evaluate institution-wide palliative care initiative	145 pediatric patients with cancer	Retrospective medical record review, single institution
De Graves & Aranda, (2002)	To explore the extent and the ways in which the shift from cure to palliative care was reflected in the child's medical record	Eighteen children	Retrospective medical record review, single institution
Feudtner et al. (2002)	To identify characteristics of children who die in hospitals including those of children dying of a complex chronic condition and to determine if children with such conditions have longer periods of mechanical ventilation before death	13,761 deaths examined	Retrospective study using data from the National Association of Children's Hospitals and Related Institutions
Feudtner et al. (2001)	To identify trends during the past 20 years in the pattern of deaths of children with complex chronic conditions	1.75 million deaths examined (5% of which were cancer-related)	Retrospective cohort study using death certificate data and estimates from the National Center for Health Statistics
Hongo et al. (2003)	To analyze the signs and symptoms of suffering as well as the acceptance of end of life in children with cancer	Twenty-eight children	Retrospective medical record review, single institution
Klopfenstein et al. (2001)	To describe the variables influencing end-of-life care in children and adolescents dying of cancer	146 children with cancer.	Retrospective medical record review, single institution
Kurashima, et al. (2005)	To identify factors associated with location of death of patients receiving palliative care in a pediatric oncology unit	Seventy-one patients receiving palliative care	Retrospective medical record review, single institution
Postovsky et al. (2004)	To evaluate the frequency and timing of "do not resuscitate" (DNR) orders among pediatric oncology patients with progressive solid tumors	Thirty-six pediatric oncology patients with progressive solid tumors	Retrospective medical record review, single institution
Tan et al. (2006)	To investigate clinical and demographic factors affecting end-of-life decisions and pediatric palliative care	Medical records of 236 children	Retrospective medical record review involving deceased patients who had received care at four specialty units, single institution

of medical record review. The focus of two publications was unique amongst the nine; one on the shift noted in medical record documentation when the goal of care changed from cure to end of life (DeGraves & Aranda, 2002), and the other on the signs and symptoms present at end of life (Hongo et al., 2003). The remaining seven focused on the characteristics of end-of-life care and two to seven of these included information on variables such as location of death, frequency, and timing of "do not resuscitate" orders, and frequency of withholding therapy or withdrawal of life support (Bradshaw, Hinds, Lensing, Gattuso, & Razzouk, 2005; Feudtner et al., 2002; Feudtner et al., 2001; Klopfenstein, Hutchinson, Clark, Young, & Ruymann, 2001; Kurashima, Latorre, Teixeira, & Camargo, 2005; Postovsky, Levenzon, Ofir, Ben, & Arush, 2004; Tan, Totapally, Torbati, & Wolfsdorf, 2006). One included the frequency of sibling counseling and bereavement counseling for the

family as well as the wishes or preferences of the patient/family regarding end-of-life care (Bradshaw et al, 2005). The nine publications were from six different countries: Israel, Brazil, Australia, Japan, Canada, and the United States (Table II).

Six publications (23.1%) involved parent-reports only. Two were specific to care-related stressors of the bereaved parents (Freeman, O'Dell, & Meola, 2004; Kreicbergs et al., 2005) and a third publication focused on bereaved parents' guilt related to their perceptions of inadequate care for their child and the relatedness of the parent guilt with symptoms of depression in these bereaved parents (Surkan et al., 2006b). One was focused on the relationship between location of the child's death and the parents' awareness of the child's pending death (Surkan, Dickman, Steineck, Onelov, & Kreicbergs, 2006a), and one on the symptoms of the dying child's last month as recalled by the parents

**Table III.** Staff-Reported Outcomes

Author	Study purpose	Sample	Design	Staff report/methods
Fowler et al. (2006)	To determine the physician comfort level dealing with end-of-life care, frequency of hospice referrals, perceived barriers to referrals, and potential solutions to these obstacles	632 pediatric oncologists	Identified eligible pediatric oncologists by using the COG website. The survey was created and tested by physicians	Survey available online (19 multiple choice items) regarding physician demographic information, education, and training in end-of-life care, comfort level in treating end-of-life pain and psychological stress; availability of hospice services, barriers to referral to hospice care and factors that could increase referral to hospice.
Friedrichs-dorf et al. (2005)	To evaluate the provision of palliative and terminal care for children with cancer in Germany	Seventy-one pediatric cancer departments (head of the oncology department and head nurse at each unit)	Survey, multi-site institutional participation	Survey developed for this study; with Likert scale, yes/no, open-ended, and continuous, noncategorical visual analogue scale responses; questions included focus on timing of breaking bad news, place of death, funding of palliative care, coordinating inpatient and at home palliative care, bereavement needs of siblings and parents and other end-of-life care variables.
Jones (2006)	To identify the social workers' perspectives regarding the psychosocial needs of children with cancer at the end of life and their families	131 members of the American Pediatric Oncology Social Workers (APOSW) Association	Focus group and survey questionnaires	Likert-type questionnaire items and open-ended questions
Mitchell et al. (2005)	To identify the patterns of psychosocial support provided by pediatric oncology treatment centers in the United Kingdom	Twenty-three centers	Questionnaire developed for this study	Closed and open-ended items related to staffing, number of patients treated, support services and activities, transition support, among others.
Solomon et al. (2005)	To determine the extent to which physicians and nurses in pediatric specialties agree with one another and with published ethical recommendations regarding the withholding and withdrawing of life support, provision of adequate analgesia and the role of parents in end-of-life decision-making	781 clinicians including 209 attending physicians, 116 house officers, and 456 nurses	Mailed questionnaire	Questionnaire developed for this study that contained opinion items, knowledge items, and belief items.

(Jalmsell, Kreicbergs, Onelov, Steineck, & Henter, 2006). One research letter reported bereaved parents' perceptions about participating in a study related to their child's end of life (Kreicbergs, Valdimarsdottir, Steineck, & Henter, 2004). Five of the six publications (Jalmsell et al., 2006; Kreicbergs et al., 2004, 2005; Surkan et al., 2006a, 2006b) are derived from the same

population-based nationwide survey in Sweden. The remaining report is from the United States (Table III).

Five publications (19.2%) involved staff-only reports. One report involved physician survey responses regarding hospice referral patterns and barriers (Fowler et al., 2006), one reported focus group and survey responses from social workers regarding their perceptions of the

**Table IV.** Parent-Reported Outcomes

Author	Study purpose	Sample	Design	Parent report/methods
Freeman et al. (2004)	To identify problems and useful resources important to parents of children with brain tumors	139 parents from 87 families whose child had been treated for a brain tumor; 15 families (29 parents) participated in the end-of-life portion of the questionnaire	One-time mailed questionnaire	Questionnaire created for this study that had items specific to each phase of care including end of life
Jalmsell et al. (2006)	To study symptoms in children with malignancies during the last month of their lives	449 parents who had lost a child to cancer	Population-based nationwide survey	Anonymous postal questionnaire with items about symptoms that affected the child's sense of well-being during the final month of life.
Kreicbergs et al. (2005)	To identify potential care-related stressors in parents whose child died a cancer-related death	449 parents of children who died from cancer in Sweden	Retrospective, population-based, nationwide survey sent to all eligible participants	Anonymous postal questionnaire
Kreicbergs et al. (2004)	To assess the harm and benefit of bereaved parents completing a questionnaire regarding their deceased child's care and death	Seventeen parents from Sweden participated in the pilot; findings were used to refine the study questionnaire for subsequent use in a study that involved 432 parents of deceased children secondary to cancer in Sweden	Questionnaire administration one-time	Parent responses to a 129-item survey regarding parent perceptions of their child's care and death as well as their perceptions of participating in a study about their child's death
Surkan et al. (2006a)	To assess the relationship between place of end-of-life care and possible predictors related to parental awareness of the child's impending death and to examine symptom relief relative to place of end-of-life care	449 parents who had lost a child due to a malignancy between in Sweden	Retrospective population-based study	Anonymous postal questionnaire
Surkan et al. 2006b	To identify predictors of feelings of guilt in parents during the year after their child's death	449 parents in Sweden whose child died a cancer-related death	Retrospective, population-based survey	Responses to a mailed 129-item questionnaire

psychosocial needs of pediatric oncology patients at end of life (Jones, 2006), one was a summary of survey findings from physicians and nurses regarding their concerns of conscience, knowledge, beliefs about pediatric end-of-life care as well as awareness of and agreement with relevant published guidelines (Solomon et al., 2005), the fourth included reports from coordinators of 23 different pediatric oncology treatment centers regarding the types of psychosocial support provided at their centers (Mitchell, Clarke, & Sloper, 2005), and the final report included summary findings from surveys completed by physicians, pediatric nurses or members of the psychosocial team regarding breaking bad news, location of death, funding of palliative care, bereavement services,

and other end-of-life care variables (Friedrichsdorf, Menke, Brun, Wamsler, & Zernikow, 2005). These five publications were from Germany ( $n = 1$ ), the United Kingdom ( $n = 1$ ) and the United States ( $n = 3$ ) (Table IV).

The final publication category ( $n = 2$ ) (7.7%) included a medical record review for 28 deceased patients and interviews with eight bereaved couples regarding the location of death and the problems associated with providing terminal care (Fujii et al., 2003). This publication was from Japan. The second publication in this category included parent ( $n = 144$ ) and physician ( $n = 52$ ) perspectives plus review of medical records regarding indicators of high quality care at the end of life for children with cancer. Parents were interviewed and

**Table V.** Other Reported Outcomes

Author	Study purpose	Sample	Design	Parent report/methods	Staff report/methods
Fujii, et al. (2003)	To analyze one hospital's experience with terminal care for children with cancer	Records of 28 children who died after treatment for cancer at one hospital in Japan and interviews with eight sets of bereaved parents	Retrospective medical record review and face-to-face interview	Questionnaire developed for data extraction from medical records, use of seven questions posed using a semi-structured method; the questions were focused on psychosomatic illness of parents following their child's death, current thoughts or feelings about the child who died, sibling's reactions to child's death, communication difficulties in every day life, source of support during bereavement	None
Mack et al. (2005)	To determine parent and physician perspectives on quality of end-of-life care and factors that influence the quality	144 parents of children receiving treatment for cancer and 52 pediatric oncologists	Retrospective institutional study	Interview (mean of 3.2 years after the death of their child)	Standardized questionnaire to primary oncologist

physicians completed surveys (Mack et al., 2005). This report was from the United States (Table V).

## Discussion

The results of this review of a recent 5-year period of publications indicates that less than 17% of the published data about end of life in pediatric oncology patients includes actual PRO or perceptions. This means that the great majority of available literature informing us about end-of-life for children and adolescents with cancer is based primarily upon medical record reviews and to a lesser extent, staff and parent observations. Similarly, a conclusion included in a recently released federal report was that no measures or indicators currently exist to evaluate the quality of supportive pediatric cancer care, whether based in patient, parent or other reports (Lorenz et al., 2006). This conclusion was based on a review of three data bases covering the years of 1995–2005 for symptom and end-of-life care instruments. This lack of PRO in the pediatric oncology literature is startling, given published recommendations from the Institute of Medicine, the Family Centered Care Institute, and the American Academy of Pediatrics for patient- and family-centered care to be individualized in ways that reflect patient priorities and care goals (American Academy of Pediatrics, 2000; Field, and Behrman, 2003).

To fully evaluate the effectiveness of our care, we need to ask those who receive it including the children and adolescents with cancer who are at end of life. End of life is a personal experience unique to each child or adolescent; for health care providers to elicit the child's experience and personal preferences, they will need to directly ask the children or adolescents for their perspective health care providers. PRO alone are not sufficient to provide expert patient- and family-centered care. A comprehensive assessment of care provided to the child or adolescent at end of life secondary to cancer or its treatment would include provider reports of toxicity, disease progression, and other measures of disease status plus measures of actual care quality and effectiveness. The latter measures particularly yield clinically useful findings when they are completed by the patient experiencing the care. In the four publications in this study that included PRO, none relied solely upon patient reports but included other sources i.e., parent, staff, or medical record data. This seems a reasonable approach given the (a) reliance upon proxy reports in studies of pediatric patients and the interest in comparing patient perspectives with those of formal and informal (family) caregivers, (b) concern that pediatric patients at end of life may not be able to report or to report in a reliable and valid manner, and the (c) likelihood that at some point in the care trajectory, the parent- and staff-reports will necessarily be the only available reports to guide care. To insure the likelihood of soliciting the pediatric

oncology patient's report, the child or adolescent's voice needs to be sought before the voice is no longer able to report. Having reliable and valid indicators of quality care available for use by clinicians, family members or researchers will very likely facilitate the solicitation of the pediatric patient's perspective at end of life and the development of indicators of quality care at end of life.

While soliciting PRO would seem to be a reasonable clinical course, the findings from this review indicate that PRO at end of life in pediatric oncology are rarely formally solicited. In our experience, clinicians have shared their hesitation to directly, formally solicit patient-reported preferences and outcomes because of concerns about offending the already emotionally burdened family and because to have such a discussion confirms the sad reality of this child's dying. These clinician concerns are quite similar to the reasons offered by clinicians for not referring patients and their families to end-of-life studies in pediatric oncology (Hinds, Burghen, & Pritchard, in press). Having validated instruments and other guides as well as assistance in using these instruments may help facilitate interactions wherein PRO and preferences at end of life will be more likely to be solicited.

Certainly there are recognizable situations when seeking the pediatric oncology patient's report will not be possible because of clinical conditions (such as sedated or obtunded patients), the developmental status of the ill child (i.e., not cognitively able to self-report), or family culture in which asking the child about end-of-life care or symptoms is culturally unacceptable. Not having reliable and valid instruments sensitive to end of life in pediatric oncology patients is *not* an acceptable clinical explanation for not soliciting the child's voice at end of life. Instead, this lack of appropriate instruments is basis for a research mandate to develop, test in relevant patient groups, and establish a repertoire of such self-report instruments. This research mandate needs to include the systematic evaluation of patient-reported instruments at end of life and the impact of such instruments on the care given and to move toward a practice standard that includes documenting why a child or adolescent's report is *not* solicited. A promising starting point in such a research mandate could be the systematic assessment of existing validated pediatric instruments for their sensitivity and appropriateness for use in pediatric oncology with patients at end of life.

The 26 publications included in the study sample were from a total of nine countries with 11 being the highest number from a single country and in this instance, from the United States. Five publications were from Sweden and all five were based on the same

population-based sample of bereaved parents. Each of the five publications focuses on a unique set of variables within the database but it is important for readers to recognize that the multiple studies are derived from the same group of participants in order to more accurately interpret generalizability of study findings beyond this one group of participants.

There are important limitations to our review, including that we did not assess the strength of the methods used in each report to solicit the patient, parent, or staff perspectives or the tools used to extract and document medical record data. We also did not formally evaluate the strength of the evidence within or across the different categories of reports given the paucity of reports in any single area of study focus and the minimal amount of overlap amongst the diverse publications. The absence of instruments with traditional psychometric characteristics reported may well reflect the early state of the science in pediatric end-of-life research as well as in patient-reported outcomes. Our summarized findings and impressions from the 35 publications could serve as a useful baseline for future summaries of empirically based literature about end-of-life care for pediatric oncology patients and their family members.

## Conclusions

Review findings indicate a measurable paucity of PRO publications. The reasons underlying the paucity could be multiple and diverse in nature but the first step in addressing this dearth is a commitment to asking the seriously ill and dying child or adolescent with cancer for their ratings, opinions, and preferences related to their care. It is this commitment that will galvanize a research priority to develop, test, and translate into clinical situations the necessary reliable and valid instruments to solicit and document the patient reports on their unique experiences at end of life.

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