

This material is protected by U.S. copyright law. Unauthorized reproduction is prohibited. To purchase quantity reprints, please e-mail reprints@ons.org or to request permission to reproduce multiple copies, please e-mail pubpermissions@ons.org.

Physical Symptoms of Children Receiving Pediatric Hospice Care at Home During the Last Week of Life

Verna Hendricks-Ferguson, PhD, RN



This article has been chosen for a podcast conversation with Verna Hendricks-Ferguson, PhD, RN. Hendricks-Ferguson lectures on and studies palliative and end-of-life care communication with children diagnosed with cancer and their parents. She has experience in pediatric oncology working with nurses during this difficult period of care. To access the podcast, visit www.onsforum.org.

Purpose/Objectives: To identify symptoms of greatest parental concern on the last day and during the last week of their children's lives, the five most common symptoms of parental concern, and symptom-management strategies used during the last week of the children's lives.

Research Approach: Descriptive, exploratory, and retrospective.

Setting: A pediatric hospice program in St. Louis, MO.

Participants: Convenience sampling of 28 bereaved parents.

Methodologic Approach: The Krippendorff method for semantical content analysis of data collected from semistructured telephone interviews with parents.

Main Research Variables: Parents' perceptions of their children's symptoms and symptom-management strategies.

Findings: On the last day of life, change in the children's breathing was the most frequent symptom of concern. During the last week of life, loss of motor function was the most frequent symptom of concern. Physical comfort actions and use of pharmaceutical agents were the strategies perceived as most helpful in managing symptoms.

Conclusions: The study is the first to document parents' perceptions of their children's symptoms and of symptom-management strategies during the last week of life while receiving care in the home from staff of the pediatric hospice program.

Interpretation: Symptoms experienced by dying children during the last week of life and symptom-management strategies used by pediatric hospice programs to support dying children and their families have not been well described. Additional research is warranted to further identify pediatric symptoms at the end of life and effective symptom-management strategies.

Key Points . . .

- A universal desire of parents is that their children are comfortable and without pain when receiving care from a pediatric hospice program.
- Little research has been conducted about the symptoms suffered by dying children in the last week of life.
- Symptom management is a key concern for parents during their children's pediatric hospice care.

& Burns, 2006). Approximately 72% of deaths occur in the hospital (56% inpatient and 16% in outpatient hospital sites), 11% at home, and 0.4% in nursing homes (Bartell & Kissane, 2005; Institute of Medicine, 2003). Suffering is at greater risk for dying children in a cure-focused culture, such as that of hospital settings without a palliative care program (Kane & Primomo, 2001). Parents' perceptions of the quality of their children's EOL has not been well documented (Davies et al.,

Verna Hendricks-Ferguson, PhD, RN, is a professor in the Goldfarb School of Nursing at Barnes-Jewish College in St. Louis, MO. This research was funded by an ONS Foundation nursing research grant, a postdoctoral fellowship through a National Research Service Award Institutional Research Training Grant from the National Institute of Nursing Research, and the Indiana University School of Nursing. No financial relationships to disclose. (Submitted August 2007. Accepted for publication January 22, 2008.)

Digital Object Identifier: 10.1188/08.ONF.E108-E115

A growing national concern of healthcare professionals is to improve the end of life (EOL) for children (Field & Behrman, 2003; Kane, Hellsten, & Coldsmith, 2004). Each year in the United States, approximately 55,000 children die from cancer (Carter et al., 2004; Troug, Meyer,

2007), and few studies have examined parental perceptions of their children's symptoms and symptom management after referral to a hospice program (Collins, Stevens, & Cousens, 1998; James & Johnson, 1997).

Literature Review

Healthcare providers must be able to anticipate the symptoms experienced by children during EOL. Little has been reported about the type and severity of symptoms suffered by dying children in the last week of life (Cooley et al., 2000; Drake, Frost, & Collins, 2003). Common symptoms documented among adults receiving hospice care include pain, dyspnea, constipation, anorexia, skin problems, and incontinence (McMillan, 1996; McMillan & Small, 2002; Petrosino, 1985). Parents of children with a brain tumor have reported dissatisfaction with the lack of information they received at the hospital regarding their children's symptoms and symptom management during the dying process (Freeman, O'Dell, & Meola, 2004).

A universal desire of parents is that their children are comfortable and free of pain (Meyer, Burns, Griffith, & Troug, 2002). Unfortunately, parents in three studies reported that pain was a frequent problem for their dying children in the hospital during the last month of life. Goldman and Chir (2000) reported that 92% of 152 children had pain. Wolfe et al. (2000) reported that 80% of 103 parents indicated that their children had pain. The parents in both studies reported fatigue and dyspnea as other frequent concerns. In addition, Kriebel et al. (2005) reported that 45% of 431 parents indicated their children had pain that could not be relieved.

Reports of the incidence of respiratory symptoms during EOL among adults with cancer have ranged from 12%–70% (Bruera, 1993). Hain, Patel, Crabtree, and Pinkerton (1995) reported that 40% of 86 children with cancer suffered from respiratory symptoms the last three months of life. The researchers concluded that respiratory symptoms are as common in children dying from cancer as in adults. Other reported symptoms experienced by dying children include seizures, cough, difficulty swallowing, vomiting, constipation, muscle spasms, oral secretions, and skin disorders (Collins, Stevens, & Cousens, 1998; Hunt, 1990).

The knowledge base of symptom-management strategies for children during EOL is limited (Wolfe, Frieber, & Hilden, 2002). In a study of pediatric hospice care (Vickers & Carlisle, 2000), all of the parents reported that their children's pain was controlled and most described their children's death experiences as quiet and peaceful. More research on parental perceptions of symptom-management strategies for children during EOL is needed as a basis for interventions to enhance their quality of life (Hughes et al., 2005; Kriebel et al., 2005; Mack et al., 2005).

The present study was guided by the Quality-of-Life EOL Model (Nuss, Hinds, & LaFond, 2005) for examining parents' perspectives of their children's symptoms during the last week of life. The primary aims of the study were to identify symptoms displayed by children that most concerned parents on the last day and during the last week of the children's lives while receiving care from a pediatric hospice program, the five most common symptoms of concern on the last day of the children's lives and during the last week of life, and symptom-management strategies used to manage the children's symptoms during the last week of life.

Methods

Design

This pilot study used a descriptive, exploratory, and retrospective design. Telephone interviews were conducted with parents using open-ended questions to elicit perceptions of their children's symptoms and of the symptom-management strategies used during the last week of life. Semantic content analysis (Krippendorff, 1980) was used to describe responses following four sequential steps: first, each phrase of every response to interview questions were analyzed for meaning (i.e., symptom, symptom-management strategy) and categorized according to those meanings; second, each categorized meaning was counted for frequency; third, labels were applied to categorized phrases; and fourth, a dictionary was developed, defining each factor. Hinds et al. (2005) described this method in a study focused on patients' preferences during EOL.

Many of the eligible participants did not live close to the principal investigator's (PI) office; therefore, conducting telephone interviews facilitated access to a greater number of participants. Compared to face-to-face interviews, telephone interviews also would help parents to feel more comfortable and to offer more honest information (Lavrakas, 1987), an important consideration given the sensitive nature of a study with bereaved parents.

Training and Consultation

The PI was trained at St. Jude Children's Research Hospital (SJCH) in Memphis, TN, by a senior nurse scientist mentor who had extensive experience in conducting telephone interviews with bereaved parents in semantic content analysis and in studies related to EOL for children with cancer. The PI met with the mentor at SJCH for training on conducting telephone interviews and to perform content analysis. In addition, the mentor assisted in describing the findings.

Sample

Using a convenience sample, parent participants were recruited exclusively from the Barnes-Jewish Hospital Wings Pediatric Hospice Program in St. Louis, MO. The hospital does not have an inpatient hospice program. Initially, the hospice staff screened potential participants, distributed study materials, and mailed the signed consent to the PI. The PI validated parent eligibility prior to calling parents to arrange telephone interviews. Parent inclusion criteria were mother, father, or legal guardian of a child who had died 6–36 months previously and who had received care by the hospice program during the last week of life, were present with the child during the last week of the life, were able to understand and speak English, and had telephone access.

Data Collection Procedure

Institutional review board approval was obtained for the data-collection setting prior to recruitment. Parent participants were recruited between 2004 and 2006. A hospice staff member initially sent parents an introductory letter describing the study, the consent form, and a list of open-ended questions that would be used in the interviews (see Figure 1). A postage-paid response card was included for parents to indicate their interest in participating. If the response card was not returned within 14 days, a hospice staff member called the parents to confirm receipt of the introductory letter. The PI telephoned consenting participants,

1. Please tell me about the symptom(s) that your child had and that concerned you the most on the day that your child died. The symptom may be physical (e.g., how your child's body showed something was different), behavioral (e.g., the way your child looked or what your child did or said), or emotional (e.g., the way your child showed feeling).

Did any of these symptoms stay the same all day, get better, get worse, or vary (e.g., times being better, then worse, then better and so forth)?

Same

Better

Worse

Vary
2. Please also tell me about the symptom(s) that your child had and that concerned you the most during the last week of his or her life. Again, these symptoms could be physical, behavioral, or emotional.

Did any of these symptoms stay the same all week, get better, worse, or vary?
3. During the last week of your child's life, what did you or anyone else do to relieve or help your child's symptoms?
4. During the last week of your child's life, what did you or anyone else do that made the situation worse for your child?
5. During the last week, what else could anyone have done to help your child?

Figure 1. Interview Questions

answered their questions, and clarified the study's purpose and the parents' role in the study. All taped interviews were assigned a random study number and locked in a file cabinet in the PI's office to ensure confidentiality. Subsequently, interviews were scheduled and ranged from 45 minutes to 3 hours.

Data Analysis

The audiotaped interviews were transcribed verbatim and checked for accuracy by two members of the study. Each phrase of every response was analyzed for meaning and colated into a table. Two members of the study team jointly reviewed the transcripts and assigned categories to key phrases. The categories were grouped into broader groups and labeled as factors. A dictionary was developed to define each factor representing symptoms and symptom-management strategies. A strength of this qualitative method is that the researchers categorized the data and counted the frequency of analyzed responses. Other members of the study team then verified the accuracy of the analyzed data from the transcripts.

Inter-rater reliability was estimated after each of the first 10 interviews and subsequently after each third interview. Reliability estimates for each factor ranged from 95%–100% across all interviews. Content analysis and use of factors has been particularly useful in explaining the qualitative findings that resulted from other data-collection methods used in previous EOL studies focused on dying children and their parents (Hinds et al., 1997, 2000, 2001, 2004, 2005).

Results

Thirty parents were invited to participate in the study. Two of the parents were not included in the study results because one parent's phone had been disconnected and another parent withdrew because of an impending divorce. The remaining 28 parents verbalized a desire to help families caring for a dying child.

The sample included 19 mothers and 9 fathers, and the parent interviews were based on the care of 19 children.

Ethnicity included Caucasian (n = 25), African American (n = 2), and Asian (n = 1). Most of the parents were married (n = 22), and their ages ranged from 27–53 years with a mean of 40 years. No other demographic information was collected.

The diagnoses of the 19 children primarily were childhood cancer: high-grade brain tumors (n = 12), leukemia (n = 1), and bone tumor (n = 1). Other childhood diseases were congenital heart defects (n = 2), renal disease (n = 1), cystic fibrosis (n = 1), and a congenital syndrome (n = 1). The age range of the children was 1 week to 18 years; only a few children were in the infant and toddler age range (see Table 1). Most children were Caucasian. Because most children die in the hospital without a hospice referral, recruitment was limited and resulted in a heterogeneous population of parents of children with varied diagnoses. The study was expanded to include parents of children with varied life-threatening illnesses because of the uncertainty of recruitment of grieving parents after the loss of a child. The convenience sample fostered the success of recruiting the 28 parents during the two-year time frame of grant funding.

None of the children was receiving chemotherapy or supportive interventions, such as oxygen, urinary catheter, or IV fluids. All of the children were prescribed morphine to control pain; however, specific dosages were not collected. All of the children were placed on a do-not-resuscitate order prior to hospice care referral. The length of time that the 19 children received hospice care ranged from 1 day to 9 months; 16 children from 1 day to 4 months, 1 child for 6 months, 1 child for 8 months, and 1 child for 9 months.

Parent responses regarding symptoms of concern during the last day and week of their children's lives are outlined in Tables 2 and 3, respectively. Likewise, responses regarding symptom-management strategies are outlined in Table 4. Categories of symptoms and symptom-management strategies are listed in the first column of each table as factors.

Table 1. Demographics of Deceased Children

Variable	n	%
Gender		
Male	10	53
Female	9	47
Developmental stage		
Infant (1 week–1 year)	2	11
Toddler (1–3 years)	3	16
Preschooler (3–6 years)	5	26
School age (7–11 years)	4	21
Adolescent (12–19 years)	5	26
Race		
Caucasian	17	90
Asian	1	5
African American	1	5
Diagnosis		
Brain tumor	12	64
Leukemia	1	5
Bone tumor	1	5
Congenital heart defect	2	11
Renal disease	1	5
Cystic fibrosis	1	5
Congenital syndrome	1	5

N = 19

Table 2. Parents' Perspectives of Symptoms Experienced on the Last Day of Their Children's Lives

Factor	Definition	Parents (N = 28)		Frequency of Factors (N = 145)		Example Quote(s)
		n	%	n	%	
Breathing difficulty	Increasing change in respirations (e.g., shallow, heavier, deeper, labored, ragged, gasping, intermittent, death rattle, apnea)	16	57	80	55	"The major thing was the breathing." "Kind of a ragged breathing" "Must be a death rattle" "Gasping for hours"
Loss of motor function	Loss of physical abilities (e.g., inability to walk, use arms, swallow, speak)	9	32	15	10	"He could not walk." "She could not speak." "He could not swallow."
Changes in energy level	Increasing fatigue, listlessness, and decreasing wakefulness	8	29	16	11	"She was extremely tired." "I remember the total listlessness."
Changes in heart rate and febrile status	Fluctuation in cardiac function and body temperature	4	14	7	5	"His heartbeat was slowing down." "Temperature out of control"
Changes in optic function	Changes in appearance of eyes (e.g., inability to close or blink, blood shot, cloudy appearance)	2	7	6	4	"He could not blink." "Very cloudy looking eyes" "They were completely bloodshot."
Disturbing body movements	Unexplained movement of extremities, body stretching, and facial grimacing	2	7	14	10	"Her leg would shake." "He had some involuntary stretching and contorting of his body."
Child was in pain.	Discomfort not reduced by usual dose of pain medication	2	7	5	3	"We had to use more and more medication to keep him calm."
Unexpected epistaxis	Displayed spontaneous nose bleeding episodes	1	4	4	3	"The onset of nose bleeds" "His second nose bleed occurred that evening."
Reaction to morphine	Unexpected rash from pain medication causing discomfort for child	1	4	3	2	"Caused her to itch real bad—that was really distressing to her."
No symptoms	No specific symptoms, unchanged behavior, and no pain	10	36	24	17	"She denied having pain." "She had no symptoms." "Nothing, unchanged"

Symptoms of Greatest Concern on Day of Death

Change in the children's breathing was the most frequently reported symptom of concern by parents (n = 16). A sample quote from the transcripts is, "I had her cradled with me, and I knew she was not breathing right." The next three most common symptoms reported were changes in the children's motor function (n = 9), energy level (n = 8), and heart rate and febrile status (n = 4). Three symptoms, changes in the appearance of the children's eyes, disturbing body movements, and the presence of pain, were identified by two parents. Notably, 10 parents indicated no specific symptom that caused them distress. When asked if the children's symptoms stayed the same or if they varied, those parents reported that the children's symptoms did not change.

Symptoms of Greatest Concern During the Last Week of Life

Loss of motor function and changes in energy level were the two most common symptoms of concern (n = 10). One parent said, "She was really sleepy and lethargic." The next three most common symptoms reported were breathing difficulty (n = 9); bowel, bladder, or gastrointestinal discomfort (n = 7); and presence of pain (n = 6). Of these three symptoms,

bowel, bladder, or gastrointestinal discomfort was reported most frequently.

A few parents were concerned with physical changes, including changes in optic function, changes in skin color, disturbing body movements, fever, bedsores, and changes in the odor of oral breath. Even fewer parents described evidence of emotional distress in their child (e.g., fears of going to sleep and dying, displaying a distance from family members). When asked if their children's symptoms stayed the same or varied, all of the parents indicated the symptoms stayed the same.

Symptom Relief Strategies

Physical comfort actions (n = 15) and pharmaceutical agents (n = 14) were the two most common strategies perceived as helpful in managing children's symptoms. Quotes about physical comfort included, "We constantly kept a hot water bottle on her because it seemed to be a comfort to her;" and for pharmaceutical agents, "They gave him a little morphine for pain, but he really did not require much."

The next three most common symptom-management strategies were prevention of physical symptoms (n = 11), physical closeness (n = 11), and physical presence (n = 11). A few parents reported that distraction, family support, familiar

Table 3. Parents' Perspectives of Symptoms Experienced During the Last Week of Their Children's Lives

Factor	Definition	Parents (N = 28)		Frequency of Factors (N = 266)		Example Quote(s)
		n	%	n	%	
Loss of motor function	Loss of physical abilities (e.g., use of arms, legs, voice, swallowing)	10	36	74	28	"She could not turn head."
Changes in energy level	Increasing fatigue and listlessness and decreasing wakefulness	10	36	30	11	"She was lethargic." "Not being able to play"
Breathing difficulty	Increasing change in respirations, such as shallow, heavier, deeper, labored, ragged, gasping, intermittent, death rattle, and apnea	9	32	30	11	"Changes in her breathing" "Struggling with breathing"
Bowel, bladder, or gastrointestinal discomfort	Increased diarrhea, constipation, urinary retention, upset stomach, and vomiting	7	25	33	12	"Had a lot of stomach aches, diarrhea, and vomiting"
Pain	Discomfort not controlled with pain medication	6	21	24	9	"There was pain."
Unresponsive	Decreased response to stimulation	4	14	6	2	"Was in a coma state"
No symptoms	No specific symptoms or behavior	4	14	6	2	"There wasn't anything."
Changes in optic function	Altered eye appearance (e.g., inability to close or blink, blood shot or cloudy)	3	10	9	3	"Unable to close eyes" "Eyes were bloodshot."
Fearful of going to sleep	Desire to stay awake and fear of dying	3	11	8	3	"Didn't want to sleep" "Had fear of dying"
Very irritable	Negative reaction to environmental stimulation	3	11	9	3	"Cried a lot" "Very agitated and upset"
Changes in skin color	Altered skin tone (e.g., pallor, cyanosis, discoloration)	3	11	7	2	"Started to look paler" "Has a little blueness"
Disturbing body movements	Unexplained body movements (e.g., stretching, facial grimacing)	3	11	3	1	"Had two seizures" "Had leg spasms"
Fever	Elevated temperature that was difficult to lower	2	7	5	1	"Had a high fever" "Unable to break fever"
Bedsore	Skin breakdown with deep open lesions on parts of body	1	4	7	2	"It was really hard to look at her bedsores."
Disturbing changes in infant's breath	Strong and offensive breath	1	4	9	3	"The smell of his breath, it's very metallic, acidic, a strong smell."
Seemed distant	Adolescent became quiet, preoccupied, and less talkative.	1	4	3	1	"Quiet, she had a far away look."

routine, vigilance by hospice nurses, choices, parent education, response to questions, fostered sense of control, preparation of family for impending death, and respected parental wishes were helpful.

What Made Symptoms Worse

Most parents (n = 24) indicated that nothing was done by anyone that made their children's symptoms worse. For instance, one parent said, "Absolutely not, everyone was fabulous." Three parents shared memories that caused emotional distress for their children and them. One mother and father indicated that they were unhappy with the selection of a book read to their daughter that focused on a dying girl in Japan. The focus of the book was not discussed with the parents prior to reading it to their child. Both parents indicated that the story was upsetting, she became very quiet following the reading, and they chose to not discuss the story with their daughter. The father of the child also discussed

feeling uncomfortable with being responsible for suctioning his child when the hospice nurse was not present. Another mother indicated being offended by a selection of music for her son because it had a sad tone, and the parents had requested upbeat music. The mother felt the song made her son think about things he did not want to think about when normally he tried to be positive. The mother indicated that neither parent discussed the music with him.

What Else Could Have Been Done?

All of the parents indicated that nothing else could have been done to help their children and that their children had received excellent care from the hospice staff. The parents expressed appreciation for the attention directed at pain control. Most parents believed their children were comfortable and free of pain on the last day (n = 26) or during the last week (n = 22). Only six parents reported that their children had some pain during the last week of life.

Table 4. Parents' Perspectives of Symptom-Management Strategies During the Last Week of Their Children's Lives

Factor	Definition	Parents (N = 28)		Frequency of Factors (N = 410)		Example Quote(s)
		n	%	n	%	
Physical comfort actions	Provided parent education on comfort measures, such as use of sponge to moisten oral area, hot water bottle for comfort, blankets for warmth, and comfortable clothing	15	54	83	20	"Tried to keep her mouth moist" "Gave crushed ice" "He had pillows galore." "Certain positions" "Using sweat pants that snapped up the side was very helpful."
Pharmaceutical agents	Received medications to reduce fever, to treat heart and lung symptoms, to decrease diarrhea, constipation, agitation, and pain and gave fluids for hydration	14	50	45	11	"Gave medicine for fever" "Gave medicine to keep him calm" "Gave medicine to stop diarrhea" "Giving him his pain medication"
Preventive actions for physical symptoms	Placed child in positions to minimize breathing difficulties, prevent skin breakdown, prevent discomfort from being held, prevent discomfort from lying on ostomy bag, to be more comfortable with bed sores, and used blankets to keep the child warm	11	39	52	13	"Constantly tried to switch positions to ease hip pain" "Propped her up with pillows to help her breathe better" "Propping him up helped him breathe better." "We had to protect his side because on one side he had the ostomy bag."
Physical closeness	Used strategies to maintain connected to child; someone was always holding child	11	39	34	8	"Held child for a couple of hours a day" "He liked to be held a lot." "Holding her hand" "Just laying with her"
Physical presence	Family members were always with child to foster trust and support.	11	39	38	9	"Stayed with child, sitting by her, being there with her; we never left her."
Distraction techniques	Use of a variety of measures to divert the child's attention, such as watching movies, listening to music, reading to the child, and talking to the child	8	29	40	10	"We would sing to her." "He loved his Disney movies and music." "Just read to her" "Just talking to him seemed to help"
Family support	Family members (e.g., parents, siblings, grandparents) spent time with the dying child.	5	18	16	4	"Having sibling sleep with her" "Our family was a real help to us."
Familiar routine	Strived to maintain home routine and regular daily activities	4	14	4	1	"I just did everything I did before; we tried to keep up the same routines."
Vigilance of hospice nurses	The hospice nurse consistently anticipated child's needs and was very attentive to the child's symptoms.	4	14	12	3	"They took care of those things." "She got the medicines we needed; we didn't have to run out; that was a tremendous help."
Gave child choices	Fostered the child to verbalize preferences during EOL care	3	11	15	4	"We gave him anything that would give him pleasure." "They gave her control."
Parent education	Provided information on caring for the child during EOL	2	7	3	1	"They trained us on how to do all of his care."
Responded to parent questions	Consistently provided respectful responses to parental query of child's care	2	7	13	3	"Just having the Wings Hospice nurse there to ask questions" "For her to answer the different questions"
Actions to foster child's sense of control	Fostered the personal preferences of the child during EOL	2	7	13	3	"The nurse always said, "Remember, her body may be withering but her brain is still hers."
Preparation of family	Provided information on the dying process	1	4	3	1	"They walked us through everything."
Respected parent wishes	Strived to support parental preferences in the care of the child during EOL	1	4	3	1	"We really didn't want to prolong anything, and they understood."

EOL—end of life

Discussion

Symptoms experienced by dying children during the last week of life have not been well described in the literature, nor have symptom-management strategies used by pediatric hospice programs to support children and their families. In-

terestingly, 35% of the parents in the study reported that their children had no symptom of concern on the last day of their lives; 14% of parents also reported this perception during the last week of their children's lives. These findings suggest that parents thought their children's symptoms were managed effectively when receiving EOL from the pediatric hospice

program. Also notable is that physical symptoms were the only concerns shared by the parents. In comparison, parents in other studies have been focused on physical, spiritual, and emotional concerns (Collins et al., 1998; Davies, 2005).

A slight majority of the parents in the study reported that their children's breathing difficulties caused them emotional distress on the last day of life. The finding that 32% of children in the study experienced breathing difficulties during the last week of life is comparable to the finding by Hain et al. (1995), who concluded that respiratory symptoms may cause emotional distress to many parents of children dying from cancer.

The presence of fatigue was one of the two most frequently identified symptoms of concern by the parents during the last week of the child's life and the third most common concern on the child's last day of life. The findings are consistent with Wolfe et al.'s (2000) finding that fatigue was one of the most commonly reported symptoms of concern. Fatigue at EOL has many potential causes, including the natural progression of the disease, poor appetite, anemia, and depression.

Pain was not reported as a frequent concern by parents in this study. A few parents indicated that their children's pain was not severe and some parents stated that their children's pain "was not that bad." In contrast, parents in other studies have reported their children's pain could not be relieved (Goldman & Chir, 2000; Kriebel et al., 2005; Wolfe et al., 2000). Perhaps many of the children in those studies died in the intensive care unit and experienced pain more frequently because they were still receiving aggressive treatments at EOL. In comparison, parental presence and participation in their children's care in the home may contribute to the parents' perception of children being more comfortable. The parents in the present study may have perceived that their children's physical pain was under control because they observed timely administration of pain medication to their dying children by nurses they knew and trusted in a pediatric hospice program.

Reported changes in body function were distressing to many of the parents. Perhaps these parents viewed changes in their child's body function as an indication of deterioration and impending death. The few parents who were concerned about behavioral changes (e.g., fears of going to sleep) during the last week may have felt powerless in comforting their children during this difficult time.

Most parents reported that they were given guidance by the hospice nurses in a variety of strategies to help manage their children's physical comfort. Many parents especially valued the measures that they could physically perform themselves. The usage of medications to control pain was the second most common strategy valued by parents. Some parents also cited strategies that helped them cope (e.g., respecting parents' wishes) and focused on the child (e.g., giving the child choices).

Limitations

The findings in this pilot study should be interpreted with caution because the sample was small, nonrandomized, and included primarily mothers and Caucasian parents. Furthermore, comparisons with previous studies cannot be made because of the heterogeneous sample in the study. Because the data were based on parents' memories of their child's EOL, this retrospective design may have resulted in an underestimation of the identified symptoms and symptom-management strategies. Still another limitation of the study is that specific pain medication dosages were not collected. Future

comparative studies with larger samples, a broader range of illnesses, and prospective designs are recommended.

Implications for Nursing Practice

Nurses should evaluate parents' overall concerns related to their children's EOL trajectory. Parents need education on symptoms that may be observed during their children's EOL, especially signs of possible impending death. Also important is to provide parents with information on effective symptom-management strategies during a child's EOL.

Research Implications

Currently, no consistent documentation exists regarding expected symptoms during a child's dying process or guidelines for symptom management. Future measurement of symptoms is needed to document trends of symptoms among children during EOL with the goal of preparing families and healthcare providers for these symptoms during EOL. Development of instruments also is needed to measure symptoms over time experienced by children during EOL to better understand the scope of a child's dying process.

Summary

A commitment to end the suffering of dying children and improve their quality of life is a universal goal of healthcare providers (Contro, Larson, Scofield, Sourkes, & Cohen, 2002; Kane, Barber, Jordan, Tichenor, & Camp, 2000; Kane & Primomo, 2001). A few notable studies have documented symptoms experienced by children who have died primarily in intensive care units, but the present study is the first to report parents' perceptions of their children's symptoms and of symptom-management strategies while receiving care in the home by a pediatric hospice program. Because hospice care is based on a clinical approach to foster a peaceful death, freedom from pain (Krueger, 2003), and enhanced quality of life (Corr & Corr, 1985; Cramer, McCorkle, Cherlin, Johnson-Hurzer, & Bradley, 2003), the finding of minimal discomfort at the time of death may suggest that this is a realistic goal for dying children. The most frequent report of parental concern was related to their children's breathing on the last day and loss of motor function during the last week; therefore, future research should focus on strategies for managing these symptoms. The Institute of Medicine (Field & Behrman, 2003) has called for research studies focused on reducing suffering experienced by children during all phases of palliative care. Further research is needed for preparing parents to manage their children's symptoms during EOL and on symptom-management strategies used by pediatric hospice programs (Stephenson, 2000).

The author gratefully acknowledges Pamela S. Hinds, PhD, RN, for her mentorship during the study and Joan E. Haase, PhD, RN, FAAN, for her mentorship during the postdoctoral fellowship at Indiana University. She also thanks parent participants and the staff from the Wings Pediatric Hospice, specifically Director Barbara J. Westland, Chaplain Susan Polmquist, and Social Worker J.J. Tellan, MS, MSW, CET, who assisted with the recruitment process, and Medical Director Elliott Gellman, MD, who granted approval for the study. Lastly, the author acknowledges the nurse scientist, Patricia Jamerson, PhD, RN, at St. Louis Children's Hospital in St. Louis, MO, for assisting with follow-up calls to parents.

Author Contact: Verna Hendricks-Ferguson, PhD, RN, can be reached at vferguson@bjc.org, with copy to editor at ONFEditor@ons.org.

References

- Bartell, A.S., & Kissane, D.W. (2005). Issues in pediatric palliative care: Understanding families. *Journal of Palliative Care*, 21(3), 165–172.
- Bruera, E. (1993). Research in symptoms other than pain. In D. Doyle, G. Hanks, & N. MacDonald (Eds.), *Oxford textbook of palliative medicine* (2nd ed., pp. 179–186). Oxford: Oxford University Press.
- Carter, B.S., Hawenstein, M., Gilmer, M.J., Throop, P., France, D., Whitlock, J.A. (2004). Circumstances surrounding the deaths of hospitalized children, opportunities for pediatric palliative care. *Pediatrics*, 114(3), 361–366.
- Collins, J.J., Stevens, M.M., & Cousens, P. (1998). Home care for the dying child: A parent's perspective. *Australian Family Physician*, 27(7), 610–614.
- Contro, N., Larson, J., Scofield, S., Sourkes, B., & Cohen, H. (2002). Family perspectives on the quality of pediatric palliative care. *Archives of Pediatric and Adolescent Medicine*, 156(1), 14–19.
- Cooley, C., Adeodu, S., Aldred, H., Beesley, S., Leung, A., & Thacker, L. (2000). Pediatric palliative care: A lack of research-based evidence. *International Journal of Palliative Nursing*, 6(7), 346–351.
- Corr, C.A., & Corr, D.M. (1985). Pediatric hospice care. *Pediatrics*, 76(5), 774–780.
- Cramer, L.D., McCorkle, R., Cherlin, E., Johnson-Hurzer, R., & Bradley, E.H. (2003). Nurses' attitudes and practice related to hospice care. *Journal of Nursing Scholarship*, 35(3), 249–255.
- Davies, B., Collins, J.J., Steele, R., Cook, K., Distler, V., & Breener, A. (2007). Parents' and children's perspectives of a children's bereavement program. *Journal of Palliative Care*, 23(1), 14–23.
- Davies, D.E. (2005). Talking about death with dying children. *New England Journal of Medicine*, 352(1), 91–92.
- Drake, R., Frost, J., & Collins, J.J. (2003). The symptoms of dying children. *Journal of Pain and Symptom Management*, 26(1), 594–603.
- Field, M.J., & Behrman, R.E. (Eds.). (2003). *When children die: Improving palliative and end-of-life care for children and their families*. Washington, DC: National Academies Press.
- Freeman, K., O'Dell, C., & Meola, C. (2004). Childhood brain tumors: Parental concerns and stressors by phase of illness. *Journal of Pediatric Oncology Nursing*, 21(2), 87–97.
- Goldman, A., & Chir, B. (2000). Symptoms and suffering at the end of life in children with cancer [Letter to the editor]. *New England Journal of Medicine*, 342(26), 1998.
- Hain, R.D.W., Patel, N., Crabtree, S., & Pinkerton, R. (1995). Respiratory symptoms in children dying from malignant disease. *Palliative Medicine*, 9(3), 201–206.
- Hinds, P.S., Drew, D., Oakes, L.L., Fouladi, M., Spunt, S.L., Church, C., et al. (2005). End-of-life care preferences of pediatric patients with cancer. *Journal of Clinical Oncology*, 23(36), 9146–9154.
- Hinds, P.S., Gattuso, J.S., Fletcher, A., Baker, E., Coleman, B., Jackson, T., et al. (2004). Quality of life as conveyed by pediatric patients with cancer. *Quality of Life Research*, 13(4), 761–772.
- Hinds, P.S., Oakes, L., Furman, W., Foppiano, P., Olson, M.S., Quargnenti, A., et al. (1997). Decision making by parents and healthcare professionals when considering continued care for pediatric patients with cancer. *Oncology Nursing Forum*, 24(9), 1523–1528.
- Hinds, P.S., Oakes, L., Furman, W., Quargnenti, A., Olson, M.S., Foppiano, P., et al. (2001). End-of-life decision made by adolescents, parents, and healthcare providers in pediatric oncology. *Cancer Nursing*, 24(2), 122–134.
- Hinds, P.S., Oakes, L., Quargnenti, A., Furman, W., Bowman, L., Gilger, E., et al. (2000). An international feasibility study of parental decision making in pediatric oncology. *Oncology Nursing Forum*, 27(8), 1233–1243.
- Hughes, A., Partridge, J.C., Davies, B., Cooper, B.A., Kramer, R.F., Amidi-Niouri, A., et al. (2005). Staff perceptions of barriers to pediatric end-of-life care in intensive care versus nonintensive care settings. *Pediatric Research*, 58(2), 404.
- Hunt, A.M. (1990). A survey of signs, symptoms, and symptom control in 30 terminally ill children. *Developmental Medicine and Child Neurology*, 32(4), 341–346.
- Institute of Medicine. (2003). *When children die: Improving palliative and end-of-life care for children and their families*. Washington, DC: National Academies Press.
- James, L., & Johnson, B. (1997). The needs of parents of pediatric oncology patients during the palliative care phase. *Journal of Pediatric Oncology*, 14(2), 83–95.
- Kane, J.R., Barber, R.G., Jordan, M., Tichenor, K.T., & Camp, K. (2000). Supportive/palliative care of children suffering from life-threatening and terminal illness. *American Journal of Hospice and Palliative Care*, 17(3), 165–172.
- Kane, J.R., Hellsten, M.B., & Coldsmith, A. (2004). Human suffering: The need for relationship based research in pediatric end-of-life care. *Journal of Pediatric Oncology*, 21(3), 180–185.
- Kane, J.R., & Primomo, M. (2001). Alleviating the suffering of seriously ill children. *American Journal of Hospice and Palliative Care*, 18(3), 161–169.
- Kreicbergs, U., Valdimarsdottir, U., Onelov, E., Bjork, O., Steineck, G., & Henter, J.I. (2005). Care-related distress: A nationwide survey of parents who lost their child to cancer. *Journal of Clinical Oncology*, 23(36), 9162–9171.
- Krippendorff, K. (1980). *Content analysis: An introduction to its methodology*. Newbury Park, CA: Sage.
- Krueger, K. (2003). Hospice meeting needs better than ever. *Inside Case Management*, 10(11), 5–7.
- Lavrakas, P. (1987). *Telephone survey methods: Sampling, selection, and supervision*. Newbury Park, CA: Sage.
- Mack, J.W., Hilden, J.M., Watterson, J., Moore, C., Turner, B., Grier, H.E., et al. (2005). Parent and physician perspectives on quality of care at the end of life in children with cancer. *Journal of Clinical Oncology*, 23(36), 9155–9161.
- McMillan, S.C. (1996). Pain and pain relief experienced by hospice patients with cancer. *Cancer Nursing*, 19(4), 298–307.
- McMillan, S.E., & Small, B. (2002). Symptom distress and quality of life in patients with cancer and newly admitted to hospice home care. *Oncology Nursing Forum*, 29(10), 1421–1426.
- Meyer, E.C., Burns, J.P., Griffith, J.L., & Troug, R.D. (2002). Parental perspectives on end-of-life care in the pediatric intensive care unit. *Critical Care Medicine*, 30(1), 226–231.
- Nuss, S.L., Hinds, P.S., & LaFond, D.A. (2005). Collaborative clinical research on end-of-life care in pediatric oncology. *Seminars in Oncology Nursing*, 21(2), 125–134.
- Petrosino, B.M. (1985). Characteristics of hospice patients, primary caregivers, and nursing care problems: Foundation for future research. *Hospice Journal*, 1(1), 3–19.
- Stephenson, J. (2000). Palliative and hospice care needed for children with life-threatening conditions. *JAMA*, 284(19), 2437–2438.
- Troug, R.D., Meyer, E.C., & Burns, J.P. (2006). Toward interventions to improve end-of-life care in the pediatric intensive care unit. *Critical Care Medicine*, 34(11), S373–S379.
- Vickers, J.L., & Carlisle, C. (2000). Choices and control: Parental experiences in pediatric terminal care. *Journal of Pediatric Oncology Nursing*, 17(1), 12–21.
- Wolfe, J., Friebert, S., & Hilden, J. (2002). Caring for children with advanced cancer integrating palliative care. *Pediatric Clinics of North America*, 49(5), 1043–1062.
- Wolfe, J., Grier, H.E., Klar, N., Levin, S.B., Ellenbogen, J.M., Salem-Schatz, S., et al. (2000). Symptoms and suffering at the end of life in children with cancer. *New England Journal of Medicine*, 342(5), 326–333.