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Integrative Review: Parent Perspectives on Care of Their Child at the End of Life

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This integrative review aims to describe parents' perspectives on end-of-life care for their children. Fifteen publications from a literature search of the Cochrane databases, CINAHL, MEDLINE, and PSYCHinfo were included in the review. Recurring themes included poor communication/lack of information, strained relationships/inadequate emotional support, parental need to maintain parent/child relationships in life and death, quality of care continues after the death of the child, influence of services/planning on parent/child impacts quality of life, and the difficult decision to terminate life support. No studies were identified that focused on parents' perspectives on the care their child received at the end of life. Further research that focuses on the special needs of parents at this difficult time is needed.

Key words

End of life, Children, Parents

PARENTS OF CHILDREN at the end of life need to make difficult decisions about end-of-life care. Parental end-of-life decision making includes a parent's decision to withhold resuscitation efforts or withdraw life-sustaining therapy to allow the terminally ill child to die a natural death (Rishel, 2010). Parents need information, resources, and support to make these difficult decisions. Children are a particularly vulnerable population, especially at the end of life (Jacobs, 2005), and they should play an active role in the decision-making process whenever possible. Parents have the responsibility to provide informed permission for medical care when the child is unable to contribute to the decision-making process (American Academy of Pediatrics, 1995). The first step in this process may be the decision to transition from curative to palliative care.

Palliative care is centered on improving the quality of life of patients and their families when faced with life-threatening illness, focusing on prevention and relief of suffering through early identification and careful assessment and treatment of pain, as well as physical, psychosocial, and spiritual needs (World Health Organization, 2010). The setting can be in the home or the hospital, and approaches should be based on parental wishes (Longden & Mayer, 2007). Grief can be prolonged when death is sudden (Seecharan, Andresen, Norris, & Toce, 2004). This finding lends support for further investigation into parents' experiences with end of life.

Watson, 1979, Watson, 1999, Watson, 2005) theory of caring provides support for the importance of this integrative review. Dimensions of caring reflect deep transpersonal involvement and caring as part of caring science (Watson, 1979, Watson, 2005), and they capture the human dimension of nursing, including the personal experiences of the recipient and provider of care. Caring as art, a moral ideal, is the starting point that leads to commitment and judgment, resulting in concrete actions (Watson, 1999, Watson, 2005). The goals of caring, mental and spiritual growth, finding meaning in self and others, discovering inner power and control, and promoting transcendence and self-healing (Watson, 1999, Watson, 2005), may be vital to parents of dying children. These caring moments assume that the nurse has adequate knowledge and clinical competence, and they depend on the nurse's ability to assess and understand the patient's condition and attend to it using appropriate means (Watson, 1999).

Nurses are uniquely situated to provide support to the patient and the family during this difficult time. Nurses will be involved with the patient and parent/family along the continuum, from life-saving measures to palliative care. They likely will spend extended periods with the patient, parents, and other family members, providing a large window of opportunity to help shape the experience. Simple acts of human kindness may provide the most help and comfort to patients and families during this difficult time at the end of life (Cherlin et al., 2004, Davies and Connaughty, 2002). These are caring acts that exemplify exceptional nursing care.

Purpose

The purpose of this integrative review was to describe parents' perspectives on end-of-life care for their children. The findings were intended to guide nursing care to meet the needs of parents and families at this difficult time.

Background

End of life implies the presence of a chronic disease(s), symptoms, and/or functional impairments that persist, but they also may fluctuate. In addition, symptoms or impairments resulting from the underlying irreversible disease require formal (paid, professional) or informal (unpaid) care and can result in death (Centers for Disease Control [CDC], 2004).

More than 53,000 children 19 years or younger died in the United States in 2007, the most recent year for which statistics are available (CDC, 2010). Worldwide, this number is much higher, with more than 8 million children younger than 5 years dying each year (Black et al., 2010). Children frequently die in critical care units and without palliative or end-of-life care (Brandon, Docherty, & Thorpe, 2007). In the United States, neoplasms, perinatal conditions, congenital anomalies, and sudden infant death syndrome contribute a death rate of 31.6 per 100,000 for all ages, whereas accidents and injuries are the leading cause of death for children less than 1 year of age (30.2/100,000) or between 15 and 24 years of age (37.4/100,000; CDC, 2010). Approximately 30% to 60% of child deaths in pediatric intensive care units (PICUs) are not unexpected but rather occur after the decision to discontinue life-saving treatments (Garros, Rosychuk, & Cox, 2003), providing time for therapeutic interaction with the parents. Parents' grief can be long lasting due to the unexpected and unexplainable nature of a child's death (Rogers, Floyd, Seltzer, Greenberg, & Hong, 2008), and lack of preparedness can lead to higher grief (McCarthy et al., 2010).

Nurses are in a key position to assist parents facing difficult decisions in the care of the child at the end of life. Parents of children at the end of life describe extreme emotions including numbness, despair, sadness, shock, and depression (Dighe, Jadhav, Muckaden, & Sovani, 2008). They worry about giving up hope (Brandon et al., 2007) and express guilt about saying "no" to extreme measures (Dokken, 2006). Parents often experience conflict and try to make sense of what "is" versus what is desired (Macdonald, Liben, Carnevale, & Cohen, 2008).

Nurses can support parents and families by providing family-centered, patient-centered care (Devictor et al., 2008, Longden and Mayer, 2007). Patient-centered care includes focusing on the patient's values and treatment preferences. Family-centered care focuses on communication and psychological, spiritual, and social support, and it is facilitated through open visiting hours (Devictor et al., 2008). Nursing should provide timely education, good sources of information, and descriptions of unfamiliar terms (Berg, 2006, Dighe et al., 2008, Dokken, 2006, Maynard et al., 2005, Macdonald et al., 2008). Education may help ease the process of transition to end-of-life care (Rishel, 2010).

Method

This integrative review was conducted using the technique described by Machi and McEvoy (2009). This technique involved six steps that are completed sequentially, including selecting a topic, searching the literature, developing the argument, surveying the literature, critiquing the literature, and writing the review. These steps were completed, resulting in this integrative review of the parents' perspectives on care of their child during the end of life, including the transition to palliative care and the decision to terminate life-saving strategies. Consistent themes were identified.

Search Strategy

The initial search of the Cochrane databases was completed using the search term *pediatric or child* and various combinations of *brain injury, end of life, hospice, palliative, nurse or nursing, and parent*. This search returned no results. Search of the CINAHL database was completed using the search term *pediatric or child*, with various combinations of *brain injury, end of life, hospice, palliative, nurse or nursing, parent*, with limits of English language and human subjects. This search resulted in 198 articles. A further search was completed using the terms *end-of-life decision* and *pediatric*, and 18 citations were returned. Corresponding searches completed using MEDLINE and PsychInfo returned additional 125 and 56 citations, respectively.

Abstracts of all cited publications were reviewed for relevance to this study. Initial inclusion criteria were research studies about parent or family perspectives on end-of-life care of children. Specifically, the continuum of care from cure-focused care to palliation or about the decision to transition to palliative care was identified. Because of the limited number of publications identified that met these criteria, the inclusion criteria were

expanded to include research studies about parent or family perspectives on end-of-life care in general. Additional resources were identified during the literature review process in reference lists of publications reviewed, and abstracts were reviewed in a similar manner. Publications were excluded if they did not include discussion of parent perceptions of experiences at the end of their child's life.

Results

Fifteen research studies met the expanded criteria and were included in this review (Table 1). All but three studies (Meyer et al., 2002, Seecharan et al., 2004, Widger and Picot, 2008) used a qualitative design to explore the experiences of parents and families facing end of life of their child.

Table 1. Summary of Articles Included in Integrative Review

Author (Year)	Sample	Limitations	Conclusions
Summary of nursing articles			
Data from Berg (2006)	1 mother of deceased child	One person's narrative	Many areas for improvement in end-of-life care for children and their parents.
Data from Davies and Connaughty (2002)	45 parents of deceased children	Limited information included about the study or the sample; small sample size	Policies, procedures, staff education, and further research are needed to meet needs of parents and their terminally ill children.
Data from Dokken (2006)	1 mother of deceased child	One person's narrative	Providers not aware of parental views and needs during their children's illnesses and deaths.
Data from Heller and Solomon (2005)	36 bereaved parents	Sample predominantly Caucasian and Christian; retrospective; small sample size; selection bias	Many problems with continuity of care are in the power of clinicians and organizations to fix.
Data from Maynard et al. (2005)	29 parents of children using hospice care	Sample self-selection process; selection bias; small sample	Clarification of role of hospice is needed; care pathway is proposed.
Data from Widger and Picot (2008)	39 parents of deceased children	Small sample; 1 location	Improvements in communication, relationships, care at time of death, and bereavement follow-up are needed.
Summary of palliative care articles			
Data from Cherlin et al. (2004)	12 primary caregivers of deceased patients	Did not look at different disciplines or identify studied behaviors by discipline	Identified clinician actions that were "outstanding" in parents' view and areas for improvement of care.
Data from Contro et al. (2002)	68 family members of 44 deceased children	Low recruitment response rate; selection bias	Need to improve pediatric palliative care; describes useful issues to consider in development of pediatric palliative care program

Data from Dighe et al. (2008)	Parents of 20 terminally ill children	Small sample size; study location—India	Parents have varying degrees of anticipatory grief; need more research about dealing with terminally ill children.
Summary of medical articles			
Data from Macdonald et al. (2008)	Single case study	Retrospective chart review	Recommends more research and clinical training in communication.
Data from Meert et al. (2009)	33 parents or guardians of deceased children	Single subject may not capture wide range of experiences	Identifies needs of parents' whose child died in the PICU and the importance of parent's memories in ongoing bereavement.
Data from Meyer et al. (2002)	56 parents of deceased children	Varying time between interviews and child's death 12–45 months; retrospective design; single location; small sample	Parent's perspectives on priorities for their child's end-of-life care are described.
Data from Meyer et al. (2006)	56 parents of deceased children	Small, predominantly white sample, low response, self-selection, 1 location	Parent's perspectives on priorities and recommendations for their child's end-of-life care and communication are described.
Data from Seecharan et al. (2004)	79 parents of deceased children	Small, predominantly white sample, low response, selection bias, one location	Parents reported high levels of satisfaction with care; sudden death led to stronger grief reaction.
Data from Sharman et al. (2005)	14 parents of children who had life support withdrawal recommended	Small number compared to total deaths; may not represent all parents	Past experiences and anticipation of future influence parental decision making to withdraw life support.

Findings

A variety of important areas for end-of-life care were addressed in these studies. Some of the investigators described parents' experiences at the child's end of life (Berg, 2006, Davies and Connaughty, 2002, Dighe et al., 2008, Dokken, 2006, Heller and Solomon, 2005, Macdonald et al., 2008, Maynard et al., 2005, Meert et al., 2009). A number of these investigators also focused on specific components of the experience, such as the meaning of optimal care (Davies & Connaughty, 2002), what matters most to parents (Heller & Solomon, 2005), or parents' needs in the PICU (Meert et al., 2009). Other investigators explored parents' views on parent and family perceptions about the quality of care at the end of life (Cherlin et al., 2004, Contro et al., 2002, Davies and Connaughty, 2002, Meyer et al., 2002, Meyer et al., 2006, Seecharan et al., 2004, Widger and Picot, 2008).

Although all the investigators were interested in gaining a better understanding of this experience, different methods were used. In one study, concerns of parents with a child who had incurable cancers were explored using informal focus groups for eliciting parents' attitudes toward informing their child about their diagnosis and prognosis (Dighe et al., 2008). In another study, the relationships between aspects of bereavement, gender, type of death, and overall experience were evaluated (Seecharan et al., 2004). In contrast, Sharman, Meert, and

Sarnaik (2005) had a more narrow focus on the influences on parent decision making about life support. Two individual self-report papers were found as well (Berg, 2006, Dokken, 2006).

The individual self-report papers (Berg, 2006, Dokken, 2006) provided the richest descriptions of experiences at the end of life. They provided detailed examples of many of the issues and problems that were described in other studies. Both authors wrote about their daughters' terminal diagnoses and transitions to end-of-life care. Experiences with a health care system that lacked sensitivity and providers who were unaware of parental needs or opinions related to decisions about illness and death were described. Challenges related to communication, information, relationships, services, time, resources for decision making, and giving the dying child identity also were addressed and in more detail than the other studies evaluated for this study.

Recurring themes emerged from the review of literature that characterized parents' experiences with care of their child at the end of life (Table 2). Themes were not mutually exclusive; they overlapped along the continuum of care. They represented the range of parents' concerns and experiences during their child's care. Prominent recurring themes in the readings included poor communication/lack of information, strained relationships/inadequate emotional support, parental need to maintain parent/child relationships in life and death, quality of care continues after the death of the child, influence of services/planning on parent/child impacts quality of life, and the difficult decision to terminate life support.

Table 2. Themes With Example Phrases

Themes	Example Phrases
1. Poor communication/lack of information	Inadequate or conflicting information
	Difficulty understanding what was said
	Did not know what to expect
	Lack of privacy during communication
	Poor communication about child's condition, who to ask for help
	Lack of information about hospice
2. Strained relationships/inadequate emotional support	Feelings of being avoided
	Lack of respect
	Taking an interest
	Courtesy, caring, and compassion
	Lack of compassion and emotional support
	Sadness, helplessness, hope, and worry
	Support limited by focus on cure and treatment
	Emotional distress may be related to single event
3. Parental need to maintain parent/child relationships in life and death	Maintain relationships
	Support from health care team
	Compassion
	Privacy
	Honesty
	Trust
	Receiving a memento
	Time to make decisions and to be with child
	Inclusion of other family members
4. Quality of care continues after the death of the child	Feeling informed
	Follow-up after death
	Respect

	Nonabandonment
	Welcoming environment
	Anticipation of needs
5. Influence of services/planning to parent/child impacts quality of life	Program development needed to improve:
	Pediatric hospice programs
	Bereavement follow-up
	Continuity of care
	Mutual goal setting
	Confidence in quality of care
	Communication
	Education
	What to expect at time of death
	Autopsy
	Sensitivity, empathy
	Physical cares
6. Difficult decision to terminate life support	Consideration of child's wishes
	Quality of life, pain and discomfort
	Chances for survival
	Faith
	Honest and complete information
	Emotional support
	Choices/options
	Parents' needs
	Previous experiences

Theme 1: Poor Communication/Lack of Information

Poor communication was identified in many studies (Contro et al., 2002, Davies and Connaughty, 2002, Widger and Picot, 2008). Parents expressed dissatisfaction with communication processes and information provided to them about their child's condition (Maynard et al., 2005, Widger and Picot, 2008). Likewise, Davies and Connaughty (2002) found that only 20% ($n = 9$) of parents interviewed were satisfied with communication with staff. Parents recognized that they received inadequate information about their child's condition, but they did not know whom to ask for help (Meyer et al., 2002, Widger and Picot, 2008). They reported having difficulty understanding what professionals said, and they believed that they occasionally received conflicting or confusing information (Contro et al., 2002, Meyer et al., 2002).

Inadequate information about the child's physical condition was reported as death grew closer, and this situation was compounded by parents' inability to ask the right questions. Parents did not know what to expect (Davies & Connaughty, 2002). They were confused about when death actually occurred and described two deaths, the spiritual death and the moment when life support was discontinued (Macdonald et al., 2008). Bad news was shared with parents in the nurses' station, which was a public area (Berg, 2006). Health care providers' lack of attention to parental concerns was identified as well (Dokken, 2006), and parents believed it led to diagnostic delays (Berg, 2006). A lack of provision of information about hospice services available also was expressed (Maynard et al., 2005). In summary, communication and information were insufficient and sometimes inappropriate. Parental needs were inadequately met.

Theme 2: Strained Relationships/Inadequate Emotional Support

In one study, some parents viewed relationships with health care providers as problematic, with one quarter ($n = 10$) expressing that they were not always treated with respect and one third ($n = 13$) believing they were being avoided (Widger & Picot, 2008). In this same study, 89.7% ($n = 35$) of respondents indicated they were treated with courtesy, caring, and compassion, and 92.3% ($n = 36$) believed that health care professionals took an interest in their family. These findings appear contradictory. However, most parents could describe specific negative experiences in great detail, but their overall satisfaction with care was high.

Experience with emotional issues also was a recurrent theme (Contro et al., 2002, Davies and Connaughty, 2002, Dighe et al., 2008, Dokken, 2006, Maynard et al., 2005). Parents indicated that staff did not have knowledge about providing emotional support and lacked compassion (Maynard et al., 2005). Participants believed that the health care providers focused on cure and treatment, limiting staff members' ability to support parents when cure was no longer possible (Davies & Connaughty, 2002). Parents described a variety of emotions, including sadness, helplessness, hope, worry about the child's pain and suffering (Dighe et al., 2008), and guilt (Dokken, 2006). An additional finding was that profound, lasting emotional distress can be the result of a single negative event (Contro et al., 2002). Parents reported that nurses' seemed to have difficulty supporting their wide range of emotions and indicated that they thought staff had difficulty with the change in focus away from cure.

Theme 3: Parental Need to Maintain Parent/Child Relationships in Life and Death

Several investigators described parents' perceptions of their needs during the end of their child's life (Contro et al., 2002, Davies and Connaughty, 2002). Parents expressed a desire to maintain relationships with their child through presence, words, or symbols (Meert et al., 2009), and they wanted to receive support from the health care team (Meyer et al., 2006). Failure to include or meet the needs of older siblings (Maynard et al., 2005), younger siblings, and Spanish-speaking family members was reported as significant deficiencies (Contro et al., 2002). Compassion, trust, honest communication, and privacy also were important (Meert et al., 2009).

At the time of death, nearly all parents expressed a desire to receive a memento, such as the hospital bracelet, footprints, or handprints. However, many parents were not given these mementos (Meert et al., 2009, Widger and Picot, 2008). In spite of these deficiencies, most parents conveyed satisfaction with care provided.

Time was identified as a prominent need (Davies and Connaughty, 2002, Dokken, 2006), including time to make decisions about the end-of-life options (Dokken, 2006). Parents also expressed the desire to spend private time with the child at the time of death (Meert et al., 2009, Davies and Connaughty, 2002), being allowed to cry and talk or to be silent (Davies & Connaughty, 2002). There were time concerns related to wanting more time and feeling rushed to make decisions (Sharman et al., 2005). Information, time, maintenance of relationships, and saving of a memento were all important needs described by parents.

Theme 4: Quality of Care Continues After the Death of the Child

Parent perspectives on the quality of care at the end of life provided the focus for Meyer et al., 2002, Davies and Connaughty, 2002. More than half of the sample of 52 parents of children who died in a PICU agreed or strongly agreed that they were well informed about their child's condition (86.5%), treatment options (78.8%), chances for survival (71.2%), pros and cons of discontinuing life support (67.3%), or continuing treatment (65.4%; Meyer et al., 2002). After death, parents appreciated follow-up in the form of cards, letters, or telephone calls from familiar staff members (Meyer et al., 2002, Cherlin et al., 2004).

Actions that family members of terminally ill patients considered outstanding practice included nonabandonment, respect for the patient, care of the family, facilitation of the family process, and follow-up with the family after the patient died (Cherlin et al., 2004). Nonabandonment behaviors included sitting and listening, paying attention, and getting to know the patient and family. Respect for the patient incorporated actions such as giving patients and families choices, being truthful, and explaining why things were happening. Care of the family promoted family visitation, a welcoming environment, and anticipating family members' needs. Facilitation of the family process also included welcoming family visits, signaling the family about changes, indicating closeness to death, and meeting the special needs. Parents identified humanistic practices that may be both time-consuming and nonreimbursable but are vitally important in end-of-life care (Cherlin et al., 2004), including sitting and listening to patients and families, explaining and giving choices, including family in care of the patient, and paying attention to the family after the death. Parents focused on important areas to include in provision of care rather than on recommendations for improvements in current practices. Communication, follow-up after death, honesty, respect, and anticipation of needs were important to parents, and they were the basis of their evaluation of care quality.

Theme 5: Influence of Services/Planning on Parent/Child Impacts Quality of Life

Problems identified by some participants helped direct recommendations for changes in practice (Contro et al., 2002, Heller and Solomon, 2005, Maynard et al., 2005). Contro et al. (2002) set out to elicit suggestions for improving quality of end of life care, prior to the facility establishing a pediatric palliative care program. Areas for improvement included preventable oversights in procedures or policies, inconsistent bereavement follow-up, inconsistencies between pain described by families and parents' perceptions of pain management, and poor preparation of community hospice programs to deal with pediatric patients. Aspects of services families viewed negatively included inflexibility of scheduling, disappointment with lack of availability of services when emergent needs took precedence, and the perception that care providers secretly discussed their child (Maynard et al., 2005).

Continuity and coordination of care of children with life-threatening illness were important to parents (Heller & Solomon, 2005). Continuity and coordination of care resulted in a reduction in parental frustration and hypervigilance, whereas parental sense of comfort and coherence in the hospital environment and confidence in quality of care were enhanced. Parents indicated that it freed them up to sustain "normal routines" such as taking care of other children or going to work. It also facilitated sharing of parents' and the staff's expertise and information about the child, increased potential for establishing coherent goals shared by the health care team and parents, and increased likelihood that changes in the child's condition would be recognized in a timely manner (Heller & Solomon, 2005). Consistent care in bereavement follow-up, pain management, availability of services, and shared goals between parents and caregivers were important issues for parents.

Parents were included in identifying some priorities for improvement (Davies and Connaughty, 2002, Widger and Picot, 2008). Protocol, procedure, and policy design must include the needs of parents and children and be based in principles of pediatric palliative care (Davies & Connaughty, 2002). The most frequently communicated area for improvement was communication and providing parents with information. Parents specifically requested more information about autopsy results, events surrounding time of death, and increased frequency of updates (Widger & Picot, 2008). Other priorities identified included increased sensitivity and empathy of health care professionals, as well as improved physical and bereavement care. After death, many families described feelings of abandonment.

Theme 6: The Difficult Decision to Terminate Life Support

Parents were sometimes faced with the difficult decision to terminate life support. Almost half of parents ($n = 23$) had already discussed it before being approached by a staff member (Meyer et al., 2002). Parents identified the child's quality of life, chance of getting better, pain or discomfort, likelihood of surviving hospitalization, and what they believed their child would have wanted as important factors to consider when making this decision (Meyer et al., 2002). Parents' past experiences with end-of-life decisions, the child's will to survive, understanding of the illness and resuscitation, the need to protect and advocate for the child, medical facts, and faith also were important considerations (Sharman et al., 2005).

Parents identified six areas of importance for their decision making, including honest and complete information, ready access to staff, communication and care coordination, emotional expression and support by staff, preservation of the integrity of the parent-child relationship, and faith (Meyer et al., 2006). When the decision was made, parents felt informed about the child's condition, treatment options, chances for survival, and pros and cons of discontinuing life support or treatment. Parents did not believe they had control over their child's final days, and many ($n = 13$) parents would have made decisions differently if they were provided the opportunity (Meyer et al., 2002). Parents wanted to avoid the decision entirely, and they recommended making choices early (Sharman et al., 2005). The child's needs and wishes, prognosis, and parents' need for control were important components of decision making for children at the end of life.

Limitations of Studies

Studies that met the inclusion criteria were primarily conducted using qualitative content analyses, using convenience sampling techniques through inclusion of participants who met eligibility criteria, and were easily accessible to the researchers (Hulley, Cummings, Browner, Grady, & Newman, 2007). Convenience samples provide easy access to subjects, but they provide the least generalizable form of sampling (Bluman, 2009, Polit and Beck, 2008). The quality of reports varied. Some investigators used questionnaires that had established reliability and validity (Seecharan et al., 2004). Others used questionnaires that had been developed for previous studies (Meyer et al., 2006), or interview guides or surveys that were developed for the particular study (Meyer et al., 2002, Widger and Picot, 2008). In one case, the interview guide was pilot tested to increase its reliability and validity (Contro et al., 2002). Frequently, inadequate information was provided about the instrument for the reader to have a clear understanding of the purpose of the interview or scope of information collected.

Many investigators acknowledged limitations of small sample sizes (Berg, 2006, Davies and Connaughty, 2002, Dighe et al., 2008, Dokken, 2006, Heller and Solomon, 2005, Maynard et al., 2005, Meyer et al., 2002, Meyer et al., 2006, Sharman et al., 2005, Widger and Picot, 2008). Study sample sizes ranged from 1 to 79 participants. In addition, some investigators acknowledged potential sample bias resulting from self-selection of participants (Contro et al., Contro et al., 2002, Heller and Solomon, 2005, Maynard et al., 2005, Seecharan et al., 2004).

Overrepresentation of Euro-American participants was evident, even when samples were drawn from more heterogeneous populations (Heller and Solomon, 2005, Meyer et al., 2002, Meyer et al., 2006, Seecharan et al., 2004). Many investigators did not report demographic characteristics (Cherlin et al., 2004, Contro et al., 2002, Davies and Connaughty, 2002, Heller and Solomon, 2005, Maynard et al., 2005, Widger and Picot, 2008), making it difficult to generalize findings or identify important cultural considerations.

The retrospective nature of these studies also may have influenced findings. Reports were elicited from 7 to 45 months after the child died. Although investigators remarked about the vividness of memory for these parents and other family members, there was no verification that the memories were reliable. Recall of events over time

may lead to recall bias (Callas, 2008), threatening the validity of the memories. However, memories belong to the parents and represent their reality. These memories have meaning, and they deserve consideration.

Discussion

The literature search exposed a dearth of published research addressing parents' needs during the end of their child's life. Available studies were focused primarily on a particular stage during the end-of-life continuum. A focus on parent's needs in specific circumstances, such as prolonged terminal illness or a sudden change of condition due to injury, also was lacking. The lack of knowledge in this area limits the conclusions that can be made about parental needs at this time.

The integrative review revealed important themes related to parents' needs at the end of their child's life. Many deficiencies were identified, including lack of communication and information. Parents' perception of caregivers' concern was less than they desired. Parents believed that respect was insufficient and that they were avoided. In spite of these feelings, parents believed they were treated with courtesy, caring, and compassion. Parents expressed a need for more emotional support than they received for the wide range of emotions they experienced. Some parents believed their emotional needs were inadequately met, particularly when the focus changed and cure was no longer the goal.

Nurses can encourage parents to discuss their feelings, emotions, and beliefs about their child's care, including such issues as withdrawal of life support, quality of life, likelihood of improved prognosis and/or survival, and perception of their child's comfort (Meyer et al., 2006). Pain management, educating parents about the process of assessment and intervention, ensuring that parents know who to talk to about questions and psychosocial needs, and encouraging parents to ask for family–staff meetings to gain information, clarity, and support are priorities for quality nursing care during this stressful time. Community pediatricians, religious support persons, and palliative care programs may be consulted and made available during all phases of hospitalization, not just at the end of life (Meyer et al., 2006). Hospice options should be introduced early, with clear descriptions of services available through hospice and palliative care (Maynard et al., 2005).

Continuity of care is essential, and a care coordinator throughout the child's illness, creative scheduling, portability of treatment plans, regularly documented family meetings, computer software for record keeping and communication, and staff orientation about family-centered care help ensure quality, seamless care (Heller & Solomon, 2005). Clinicians and health care organizations are obliged to identify and address existing barriers to quality care. Research and education for professionals who deal with terminally ill children must be a priority.

Nurses have an opportunity to help parents meet these needs during the difficult transition to end-of-life care for their children. Nurses must assess parents' needs for information about their child's condition. Attention is needed when determining the importance of timing, the sensitive nature of the situation, and parents' need for information. The change in focus from cure to care may make it difficult for some nurses to support parents' emotional needs. Parents may sense this discomfort and interpret it as avoidance. It is important that nurses process their own feelings first before learning and implementing specific techniques for supporting emotional needs of parents. A vital consideration is that one negative event or interaction may be remembered by parents forever, and it may cause enduring emotional distress.

Parents' perception of care quality may be improved with better communication, follow-up after death, honesty, respect, and anticipation of needs. A dedicated pediatric end-of-life service, promoting continuity of care, including provision of hospice and bereavement services may improve nurse's ability to meet parents' needs. Parents are positioned to make difficult decisions. It is important that nurses consider the prognosis, the child's needs and wishes, and the parents' need for control. Enhanced nurse–parent relationships could facilitate this decision making.

Most importantly, it is vital that nurses understand parents' perceptions of their child's end-of-life care, for example, their need for emotional support for decision making. However, little is known about this important health care issue. It is unknown whether the needs are different when the loss of the child is prolonged with chronic illness, such as cystic fibrosis, or when it is sudden and unexpected, as experienced with traumatic brain injury. In order for nurses to deliver quality, evidence-based care at this important juncture, further research is needed. A number of challenges exist when dealing with the sensitive and grief-laden nature of this experience for parents. This area of research may reveal key similarities and differences in parental experiences and needs. In addition, it is imperative that diverse samples are included to represent ethnic, racial, religious, gender, and geographic differences in parental experiences and needs. Further research may help to direct better end-of-life care for children and their parents during this very difficult time.

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