Pediatric Palliative Care and End of Life

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Intro/background info

The purpose of this project was to understand families' and patients' expectations around end of life decisions and how the palliative care team at the Dell Children's Medical Center can better meet family and patient needs. For this project, our team conducted targeted literature reviews focused on end of life decision making, family-centered care, culture/spirituality, and pain/symptom management. Our team also provided recommendations based on our findings for each domain.

Throughout the project, we worked closely with the palliative care team at Dell Children's Medical Center to better target the needs of their population. We hope this information can aide the palliative care team at Dell Children's in their mission to continuously improve their quality of care.

Quality Improvement

The PICU-QODD-20 was developed by identifying 20 items covering a full range of themes identified by focus groups with PICU clinicians, parents of children who died in the PICU, and a systematic literature review. It was based on the adult QODD questionnaire, but modified to emphasize the hopes and priorities of family members of patients, rather than focusing solely on the preferences of the patient. It was found to be a valid and reliable outcome measure of the quality of death and dying in the PICU setting. Use of this tool could help identify current barriers and gaps in care, and assist with the ultimate goal of improving end of life care for children and families being treated by palliative care teams. Table 1 illustrates the items included in the PICU-QODD-20 by domain (Sellers et al., 2015)

Pain and symptom management

1. The child was free of pain
2. The child was free of other troubling symptoms
3. Clinical staff responded quickly to parents' concerns about their child's symptoms

Communication Issues

1. Clinical staff gave parents information about their child in a way that it could be understood
2. Clinical staff prepared parents for what might happen to their child
3. Clinical staff discovered and respected parents' wishes and decisions
4. Clinical staff created an atmosphere in which parents felt comfortable asking questions about their child

Decisions to withdraw life support

1. Clinical staff offered parents opportunities to discuss options about their child's care with the health-care team
2. There were no conflicts between parents and the clinical staff about the best way to care for the child

Privacy and PICU environment issues

1. Clinical staff provided parents with privacy with their child near the end of their child's life

Physical and instrumental needs of family

1. Parents could easily meet their basic physical needs (accessible bathroom, showers, affordable meals, places to stay, parking, etc.)

Emotional needs/support of family

1. Clinical staff demonstrated that they cared about the child as an individual
2. Clinical staff supported the parents emotionally
3. Clinical staff provided parents with opportunities to be near their child

Fulfilling the parental role

1. Clinical staff helped parents find ways to touch, hold, and/or connect with their child

Spirituality and religious/cultural issues

1. Hospital clergy and chaplains were available
2. Staff discovered and respected the family's spiritual and/or religious needs

Continuity/coordination of care

1. Nurses and doctors did a good job of passing information about the child onto the next shift or rotation

Grief and bereavement

1. Clinical staff helped parents create memories (such as handprints, lockets of hair, photographs) of their child
2. Once the child died, his/her parents were allowed to stay with him/her for as long as they wanted

End of Life Decision Making

Parents often differ on the factors that will influence their decision-making including: information of interest required from the medical team, and preference for whom on the medical team provides desired information (October, Fisher, Feudtner, & Hinds, 2014; Rushton, 2005). However, there are a few characteristics that are common for most parents making end of life decisions. Parents often want the healthcare team's support and knowledge when making a decision but also want to have final authority on what decisions will be made and want this autonomy to be clear to all stakeholders (Einarsdottir, 2009). There seems to be differences in parents' interests and the information that the healthcare team provides. It has been found that when faced with making EOL decisions parents are most interested in chances for survival, quality of life, and experiences of pain and suffering. However, the palliative care teams tend to review organ systems, discuss changes in labs, with little connect to parents' concerns (Rushton, 2005).

Despite the challenging nature of planning for changes in health and ultimately a child's death, this seems to be associated with many positive outcomes. Advance care planning should include: desired location of death, predicted trajectory of illness and if desired how to be managed from home, desired treatments, and if applicable legal documents. Advanced care planning is associated with: parents and patients feeling more prepared for end of life (Dussel, Kreicbergs, Hilden, Watterson, Moore, Turner, Weeks, & Wolfe, 2009), lower levels of patient anxiety (Lyon, Jacobs, Brigs, Cheng, Wang, 2013), more positive emotional experiences for patient and family (Lotz, Jox, Borasio, & Führer, 2013), and fewer hospital visits for patients at home or fewer between or within hospital transfers when child is in the hospital (Dussel et al., 2009).

Pediatric palliative care differs from many other forms of medicine in that positive outcomes are likely to be far more dependent on quality of patient/family relationships and level of shared understanding between patient and healthcare team. This makes standardized procedures to approach palliative care patients very challenging to execute and very underrepresented in research. Instead most research focuses on more universal skills that could be useful to many children's unique needs and prognosis.

Family-Centered Care

A core component of pediatric palliative care is family-centered practice which involves the family as part of the care team, respects the need of the family and the child, and provides compassionate care "from diagnosis to bereavement," (American Academy of Pediatrics, 2000; Institute of Medicine, 2004; Jones, Contro, & Koch, 2013).

Across multiple qualitative and quantitative studies of bereaved families, parents identified honest communication and compassionate care from the health care team as key factors in the quality of their child's end-of-life care (Contro et al., 2002; Meyer, Ritholz, Burns, & Truong, 2006; Steele et al. 2013; Virdun et al., 2015). Parents emphasized the importance of receiving "honest and complete information" that presented the "big picture" of their child's treatment and prognosis (Meyer et al., 2006; Steele et al, 2013).

Two areas for improvement that were discussed across various studies was addressing the needs of siblings and improved bereavement support (Contro et al., 2006; D'Agostino et al., 2008; Jones et al. 2013). Practical recommendations to address the needs of siblings include engaging siblings in discussion of treatment in a developmentally appropriate manner providing psychoeducation to parents and other social supports about the needs of siblings, and referral to sibling support groups or other outside resources (Jones et al, 2013; Steele et al., 2013; Lane & Mason, 2014). Practical recommendations for bereavement care include immediate contact after the death of the child as well as continued follow up contact from the care team (Contro et al.,2002; Jones et al, 2013.)

Culture/Spirituality

Quality end-of-life care depends greatly on the health care team's ability to recognize a family's cultural and spiritual values and traditions. Complications can arise when the family and the team hold different values. This is illustrated by the not uncommon conflict of quantity of days vs. quality of days. This value dilemma tends to come into play when different treatment options have to be evaluated near the end of life and some families persist on their idea of further aggressive treatments.

One approach to dealing with this conflict effectively and maintaining respect for the family's values is to *actively shift the perspective by suggesting to change the vantage point and to assess what the situation looks like from this new perspective.* This process may create room and activate new thoughts and prospects. For example: Discussing DNR may conjure up the image of "doing nothing" and simply watching the child die for many families. If a provider succeeds in reaching parents emotions and contemplating with them what else can be done for their dying child—holding, lying closely, singing, praying—this mental picture of "doing nothing" may gently be changed into a less frightening one of love, closeness, and peace (Bergstraesser, 2013).

Lastly, acknowledging anticipatory grief is an important part of the grieving process and one that can be affected by the palliative care team before end of life.. Taking time to understand the process of anticipatory grief for each family, based on their cultural and spiritual values, and encouraging them to acknowledge their feelings and speak opening about the imminent death can play an important role in the family's ability to cope after end of life (Kang et al., 2005).

Domain	Recommendations
End of life decision making	• Explain to parents the child's, family's and team's roles in the decision making process and assess parent's feelings of involvement and feelings of autonomy in decision-making • The team should provide support or reassurance from their child's healthcare team about decisions • Monitor and potentially alter doctor and family talk time (families feel more satisfied and more confident with increased talk time) • The palliative care team should strive to increase provider access and availability
Family-Centered Care	• Provide families with honest and complete information that presents the "big picture" of the child's treatment and prognosis • Include siblings in the child's care in a developmentally appropriate manner • Provide bereavement services to families
Culture/Spirituality	• Focus on facilitating shifts in perspective that create room for new thoughts and prospects when there are treatment conflicts. • Acknowledge anticipatory grief and create space for the grieving process to begin before end of life. • Assess how well spiritual and cultural needs are being attended to by checking in with the family around these issues frequently.
Symptom Management	• Identify and resolve any barriers to treatment • Properly assess the child's symptoms using tools such as SSPEDI • Maintain open communication with the family and the child. Provide family-centered patient care. • Educate families on palliative care and the treatment options provided. Provide resources such as focus groups and websites where they can find more information.
Pain Management	• Education on possible obstacles in pain management should be targeted at both healthcare professionals and families to help overcome barriers so that adequate pain relief may be provided to the patient. • Explore possible ways to connect inpatient and outpatient pain management. Assistance with at home pain management after the patient goes home may be an unmet need. • Focus on building strong relationships between medical staff and families of patients. The quality of relationship between staff and families seems to be most crucial to a positive appraisal of the overall palliative care experience, including pain management.

Symptom Management

In order to have effective symptom management, the child's care team must communicate with the family and establish goals of therapy. Ideally, they should focus on improving the child's function and limiting their suffering. A child's report of symptoms is considered the gold standard for assessment (Shaw, 2012). Other assessments include parental reports, psychological and behavioral tools and indicators.

Four main categories of symptoms that are most bothersome are pain, dyspnea, GI disturbances, and neurological changes (Crozier, Hancock, 2012). Effective symptom management is hindered by various barriers. According to the American Academy of Pediatrics, the most common perceived barriers were: uncertain prognosis, family willingness to accept the incurable condition, differences in treatment goals, communication issues, and lack of education.

Communication is key in order to adequately treat the symptoms of pediatric palliative care patients. Families should be educated on the nature of the disease and possible expectations. In addition, family resources such as support groups and counselors should be offered.

Children may have many questions about their treatment and disease states. It is imperative to answer the child's question in a supportive and reassuring way.

Pain Management

It is well documented that a majority of parents feel that their child did not receive adequate pain relief at the end of life (Zernikow et al., 2009). However, a discrepancy has been noted between high levels of pain at end of life described by parents, and their belief that their child's pain was "adequately" or "well" managed. A possible explanation for this incongruity could be due to parental belief that the most advanced technology in pain relief was utilized and therefore nothing further could be done to reduce their child's pain (Contro et al., 2002).

Possible barriers to adequate pain control have been cited as non-recognition of the presence of pain, non-recognition of the global nature of pain, fear of doing harm, fear of addiction and abuse, fear of diverted use, failure of physicians to ask for assistance from pain specialists, exclusion of concurrent non-pharmacological measures, denial by parents who link pain as a sign of deterioration, and patient and parent impression that the pain must be unable to be relieved, otherwise it would be addressed by the medical team (Grégoire and Frager, 2006).

Particularly in the outpatient setting, families of pediatric palliative care patients have reported a deficiency regarding proper pediatric pain control in the hospice setting. Hospice staff admit to feeling unprepared to serve children's pain management needs. In one focus group, parents of pediatric palliative care patients reported that inadequate at-home pain management left them in need of inpatient services that were unavailable to them on an outpatient basis (Contro et al., 2002).

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