

# The Duty of the Physician to Care for the Family in Pediatric Palliative Care: Context, Communication, and Caring

## abstract

Pediatric palliative care physicians have an ethical duty to care for the families of children with life-threatening conditions through their illness and bereavement. This duty is predicated on 2 important factors: (1) best interest of the child and (2) nonabandonment. Children exist in the context of a family and therefore excellent care for the child must include attention to the needs of the family, including siblings. The principle of nonabandonment is an important one in pediatric palliative care, as many families report being well cared for during their child's treatment, but feel as if the physicians and team members suddenly disappear after the death of the child. Family-centered care requires frequent, kind, and accurate communication with parents that leads to shared decision-making during treatment, care of parents and siblings during end-of-life, and assistance to the family in bereavement after death. Despite the challenges to this comprehensive care, physicians can support and be supported by their transdisciplinary palliative care team members in providing compassionate, ethical, and holistic care to the entire family when a child is ill. *Pediatrics* 2014;133:S8–S15

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### KEY WORDS

palliative care, ethics, autonomy, relational autonomy, communication

### ABBREVIATION

AAP—American Academy of Pediatrics

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## Prologue

*A young patient who we will call Talia was diagnosed with cancer at the age of 10. Talia's 14-year-old brother loved to play soccer and was a good student. Her maternal grandmother lived with the family and quietly supported them. Talia and her parents were extremely engaging and quickly developed a strong therapeutic relationship with their medical team. The family often referred to staff as "friends" or "hospital family" and spoke of how grateful they were for Talia's care.*

*Eight months after completing her chemotherapy course, Talia experienced a disease recurrence. As Talia and her family wrestled with their shock and sadness, palliative radiation and chemotherapy were started. The palliative care team helped Talia with symptom management as well as clarifying Talia's wishes and guiding the family's expectations for the future. When Talia died fairly soon after relapse, several medical team members spoke at the service. The family was deeply moved by the support and extremely grateful.*

*Once home, the flurry of support soon disappeared. Talia's grieving mother retreated from all activities. She later reported that she felt as if she was "at the bottom of a deep crevice alone and broken." Talia's brother spent more time away from the house and told his school counselor that he was totally unprepared for his sister's death and had trouble concentrating and being around friends, "who just don't understand what I am going through". The family later expressed their profound disappointment that no one called or visited from the hospital. They felt as if the hospital staff were the ones who understood them better than anyone, but that they had vanished from their lives.*

Over the last decade, pediatric palliative care clinicians have recognized that they must not only include the family in the care of the patient but that they must also care for family members of a dying child. This broader set of responsibilities is now a core component of optimal pediatric palliative care. The Institute of Medicine Committee on Palliative and End of Life Care for Children and Their Families, for example, identified the following 3 working principles: good care involves and respects both the child and the

family; families are part of the care team; and effective and compassionate care for children who have life-threatening conditions and their families is an integral and important part of care from diagnosis through death and bereavement.<sup>1</sup> Yet despite this and other calls for a family-focused approach in pediatric palliative care specifically, and pediatric care more generally,<sup>2,3</sup> a gap remains between optimal family care and what typically happens in practice. This gap, in part, is attributable to both ambiguity and ambivalence about what "caring for the family" means: Does this mean simply showing respect for the other family members, or actually engaging in therapeutic activities for these family members? Would establishing clinician-patient relationships with other members of the family and providing such therapies as counseling or medications to grieving or depressed family members be doing the right thing or going too far? Do physicians feel that they have the time or requisite expertise to provide mental health care to families? Can they use members of their transdisciplinary team to assist with this care and potential community referrals? In this article, we argue that because the family is the greatest influence in the life of the child, and the well-being of the child and family are intrinsically linked, care for the child must include care for the family. Physicians are ethically bound to care for the family along with the child.

## CURRENT STANDARD AND RECOMMENDATIONS

The American Academy of Pediatrics (AAP) recommends that patient- and family-centered care be core to all pediatric practice.<sup>2</sup> Family-centered care is essential to pediatric palliative care because it "recognizes that the perspectives and information provided

by families, children, and young adults are essential components of high-quality clinical decision-making, and that patients and family are integral partners with the health care team."<sup>2</sup> The AAP and the Institute of Medicine each call for integrated palliative care practices through the entirety of children's medical care, from diagnosis to the end of life and bereavement.<sup>1,3,4</sup> Acknowledging that the physician's role is expanded to include caring for the entire family, and knowing that "(T)he quality of care at the end of a patient's life is very important to the family of the patient and can directly affect the way a family deals with the death of a loved one,"<sup>5</sup> this care includes guiding and supporting the family during the time leading up to a child's death. Through several policy and task force statements, the AAP and the World Health Organization underscored these same principles and others relating to the physician's roles and responsibilities in caring for a family with an ill child through death and bereavement.<sup>2-4,6-10</sup>

## ETHICAL RATIONALE TO CARE FOR THE FAMILY

Why should the physician's obligation to family members go beyond discussions of plans of care for their ill child? Beyond the inner calling to be compassionate,<sup>11</sup> 2 ethical rationales motivate this extension of duty. First, doing so is in the child patient's best interest; children exist in the context of family, and to care for the family is to care for the child. Families who have seriously ill children face numerous challenges directly arising from their child's illness. Specifically, when there is an ill child in a family, those families face strain on marriages and partnered relationships,<sup>12</sup> stress on siblings,<sup>12-14</sup> physical or mental health issues,<sup>12,15,16</sup> impacted finances or employment,<sup>12,17</sup> social

isolation or disengagement,<sup>12,18</sup> poor physical health,<sup>17</sup> loss,<sup>18</sup> concern for the future,<sup>12</sup> post-traumatic stress disorder,<sup>19,20</sup> and grief.<sup>21,22</sup> Although there is evidence to suggest that families are quite resilient in the face of their child's life-threatening condition, physician attention to the specific needs of the family can enhance that resilience.<sup>23–26</sup>

Second, the relationships forged with family members during the course of caring for seriously ill patients tap into the ethical duty of nonabandonment, a concept that serves to “acknowledge and reinforce the centrality of an ongoing personal commitment to caring and problem solving between physician and patient.”<sup>27</sup> Although physicians endorse divergent senses of how far their duty to family members extends,<sup>5,28,29</sup> to fully engage in family-centered care, the obligation of nonabandonment must be expanded beyond the patient to also encompass the family, and must endure beyond the death of the patient. Talia's family (as depicted in the opening vignette) is not unusual in feeling well cared for during the treatment process despite the outcome of treatment, yet feeling abandoned by their physicians and team members during the bereavement phase.

Can appropriate care of family members and fulfillment of these duties to pursue the best interests of the child and to adhere to the standard of nonabandonment be realized in clinical practice, especially in an era of ever-mounting concerns about health care cost? For the remainder of this article, we focus on how and what needs to be done to move us closer to these ideals.

### **FAMILY CARE PROVIDED BY AN INTERDISCIPLINARY TEAM**

Pediatric physicians should not feel as though the care of the family must be

handled only by them. Given the complexity of the care, it is unrealistic to expect that any single physician should be able to adequately address all concerns. In most hospital settings, the physician can make use of the expertise of nurses, social workers, child life specialists, chaplains, psychologists, and other members of the transdisciplinary team to ensure that families receive optimal care. In many cases, these members are already a part of the palliative care team or service.<sup>13</sup> For example, a depressed sibling might be referred for a consult with child psychiatry or a family who experiences a great deal of conflict or anxiety can be seen by a social worker skilled in family systems. Although in general medical education does not prepare physicians to practice in an interdisciplinary setting as part of a team,<sup>30–32</sup> a well-functioning interdisciplinary team provides a safety net for the family without overburdening 1 particular provider.

### **IMPROVING CLINICIAN-FAMILY RELATIONSHIPS AND COMMUNICATION**

Parents repeatedly state that compassionate communication and honest and timely discussions with physicians are critically important in decision-making for their children who have life-threatening conditions.<sup>33–35</sup> Nevertheless, parents do not always feel informed or supported in decision-making.<sup>33–35</sup> Collaborative communication promotes open conversation about decision-making, allows for ongoing assessments of family need, and takes into account the family's knowledge about the child's illness.<sup>3,13,36–38</sup>

A metasummary of qualitative analyses of patient and family needs in pediatric palliative care found that family needs are quite high, specifically in the areas of interactions with staff, psychosocial needs, spiritual issues, decision-making,

sibling needs, cultural needs, pain and symptom management, information needs, and health care delivery and accessibility.<sup>39</sup>

More specifically, in a qualitative study of parents who had recently participated in difficult conversations with physicians in the pediatric intensive care setting, 11 specific physician interpersonal behaviors were identified as helpful to parents<sup>40</sup>: empathy, availability, treating the child as an individual, respecting parents' knowledge of the child, allowing hope, body contact that communicated warmth, thoroughness, going beyond the call of duty, accountability, willingness to be questioned, and attention to the suffering of the child.<sup>40</sup> Similarly, a study with bereaved parents found that parents value these specific elements of communication from their physicians<sup>25</sup>: comprehensive and complete information; clarity of information, use of clear language; ease of access to caregivers and their explanations throughout the course of care; pacing of information, soliciting of parents' emotional responses and addressing their questions; consistency of information; honesty, lack of false hope; empathy as demonstrated by verbal, nonverbal, and affective communication; summary statements and next steps.

### **ENHANCING SHARED DECISION-MAKING**

As families face increasingly difficult treatment and palliative decisions, anticipatory guidance from the care team becomes a vital element of care. Often families feel that information is contradictory or unclear,<sup>25,30,39,41</sup> or that they do not receive adequate information to allow them to make decisions or prepare for what might affect their child next.<sup>25,39,41</sup> Families who do not speak English are especially at risk for inadequate

anticipatory guidance, owing to poor communication between the family and team.<sup>42–44</sup>

When families are being asked to make decisions that will impact the quality and length of their child's life, it is part of the physician's ethical duty to provide timely information and a pathway toward shared decision-making for the family. Physicians must support and respect families' needs to make decisions that will be best for their individual child, but they should not leave the family completely alone to make these difficult decisions. There is a fine balance between supporting and guiding a family while allowing the family the appropriate space to make their own decisions.

Family reflections on their experiences underscore the importance of effective communication and adequate information. One mother recalled that during the end of her child's illness there was a lack of anticipatory guidance for her family, leaving the family with the emotional burden of uncertainty: "when they tell you... 'There's nothing we can do', then you kind of wonder, 'what is it going to be like? What are the changes?'... it didn't seem like we had a lot of information about what it would be like."<sup>37</sup> Another parent explained her frustration with feeling as though the physician did not take into account her and her family's perspectives. This can increase isolation and threaten the family's ability to communicate openly while trusting their child's care team: "I want them (medical staff) to respect my point of view as much as I was respecting theirs...they were pressuring (me) to make decisions that I knew were not right at that time. We know that they've been taught. We are grateful for what they are doing. They do their best, but there are those times that they have to listen to parents."<sup>37</sup> Often complex family issues arise during treatment or

are a part of the family history or communication style. Attending to the holistic needs of the child in the context of their family, promoting collaborative communication, and offering anticipatory guidance from diagnosis through bereavement increases the likelihood that the tasks of pediatric palliative care will be provided compassionately and effectively.

Parents indicate that they want the physician and care team to let them make their own decisions but to stay engaged in the decision-making process.<sup>33–35</sup> Parents also request contact with other parents, specifically because they are seeking parent-to-parent social support, during the life of the child and during bereavement.<sup>42,45,46</sup> Physicians and the transdisciplinary team can stay close to families and help them connect with whatever supports they need to make the best decisions for their child. Parents need to be offered choice and control while continuing to receive the therapeutic guidance and support of the physician and team. This shared decision-making assumes that both the parent and the physician literally share the responsibility and discussion in care decisions.

### CARING FOR SIBLINGS

A family's needs are complex when coping with a child's illness, but of particular concern is the well-being of a patient's siblings. Despite a growing body of literature substantiating the needs of siblings during their brother or sister's course of illness, they continue to be unmet.<sup>13,28,47,48</sup> Siblings report that even when they are present at the hospital for long periods of time, they go unnoticed. One 17-year-old sibling explained that "the doctors, they mostly just talked to my parents, but it might have been nice to have been included in stuff like that."<sup>41</sup>

Ideally the role of the palliative care physician includes promoting the well-being of siblings through education, monitoring of mental and physical health, and ensuring referrals to appropriate resources on the team and in the community. Siblings are often neglected during the time of their brother or sister's death; "falsely protecting the siblings by exclusion during the terminal phase can lead to serious adjustment problems later; health care team members should share with parents findings in the literature that point to the benefits of appropriate sibling participation and should encourage parents to involve the siblings as much as feasible."<sup>15</sup> Siblings of children who have life-threatening conditions may experience post-traumatic stress symptoms, poor quality of life, and a sense of aloneness.<sup>49</sup> Some siblings also show positive outcomes such as increased capacity for empathy and psychological maturity. In Talia's case, her brother was a "silent sibling" during the treatment process, rarely coming to the hospital, and he was never included in medical discussions. This nonengagement in turn left him feeling unprepared, lost, and alone after his sister died. Physicians and the transdisciplinary team can provide interventions to assist siblings during the illness and through bereavement. Educational interventions with siblings of hospitalized children have been shown to decrease anxiety.<sup>50</sup> In a recent study of bereaved parents and siblings, Steele and colleagues found that the following themes emerged as recommendations for care providers: (1) improved communication with the medical team, (2) more compassionate care, (3) increased access to resources, (4) ongoing research, and (5) offering praise.<sup>37,49,51,52</sup> In practical terms, physicians can address the needs of siblings by<sup>37,49,51,52</sup>:

1. Engaging siblings in care discussions throughout the treatment process.
2. Providing a role for siblings in caregiving tasks as desired.
3. Assigning a child life specialist or social worker to specifically work with the sibling.
4. Referring to local and national resources such as support groups or *SuperSibs!*
5. Providing psychoeducation to the family about the needs of siblings.
6. Encouraging siblings to remain engaged in activities that are important to them.
7. Helping the family identify a “safe adult” in the siblings’ world that they can talk to about their feelings.
8. Making referrals to mental health professionals such as social workers or psychologists for assessment and counseling, when needed.
9. Asking siblings directly about their experience.

## PROVIDING BEREAVEMENT CARE

Talia’s mother, in the opening vignette, depicts a common reality; parental grief is intense and prolonged and can lead to a complicated mourning response that lasts for years.<sup>41,42,53</sup> Bereaved parents are at risk for anxiety, depression, suicidal ideation, prolonged grief, decreased quality of life, relationship struggles, and social decline.<sup>54</sup> When a child dies, it is a devastating and life-altering event that directly challenges the inherent parental roles of protection and nurturing. Parents may feel guilt and depression for many years after the death of a child

and may struggle to re-establish their lives.<sup>21,55</sup>

In the midst of their incredible sadness, families often report feeling abandoned by their health care team once the death occurs, creating an additional burden of experiencing the simultaneous loss of their child and their physician whom they have come to rely on not only for the medical care, but also for comfort, continuity, and information.<sup>56</sup> When there is no follow-up contact, parents struggle with feeling as though there is lack of closure with their child’s physician; “an abrupt end to contact soon after the child’s death can feel like, and be a kind of, abandonment.”<sup>1</sup> “It’s kind of interesting, because when you’ve gone through a long illness and everybody is like your family, then when your child passes, there’s that whole segment of your life that goes away,” 1 parent illustrates.<sup>37</sup>

Parents have described that when their child’s physician does reach out to them via phone they feel a sense of comfort; “I think it was really important that he [the physician] did call... it just showed me that he cared and that she just wasn’t a...just wasn’t a patient...that he treated and then she didn’t make it, so, ‘oh well.’”<sup>56</sup> Another parent explained her positive feeling of comfort when her child’s physician continued to keep in touch with the family; “We feel we are not left out. That is, we have somebody who thinks about us.”<sup>37</sup> Borasino and colleagues have also reported that such contact may also help physicians process their own feelings, yet only a low percentage of physicians reported active means of contact with the family, such as writing, calling, or meeting with family members; more often, passive means were used, such as giving families contact information at the time of death or designating other staff to offer

follow-up.<sup>38</sup> As previously stated, the pediatric palliative standard of care embraces bereavement support; however, parents’ recollections and other research have offered evidence that adequate bereavement follow-up is not occurring.<sup>56</sup> Physicians explain that their lack of time, unawareness that family members experience this lack of closure as abandonment, and personal and emotional barriers keep them from following up with families.<sup>56</sup> Specific recommendations for physicians to provide bereavement care include<sup>1,37,38,53–57</sup>:

1. Offering honest and timely information and shared decision-making in treatment and end-of-life care. Full involvement and having a sense that “everything was done” can decrease the risk of complicated mourning for families.
2. Attending the funeral or memorial service. The presence of the physician and team members is meaningful to family members and demonstrates that their child was cared for as an individual.
3. Providing follow-up contact from the physician within the first few days after the death. Parents feel very connected to the care team and need immediate contact when possible.
4. Scheduling a post-death conference with the family in a few weeks or months, depending on the family’s readiness. Having an opportunity to review the sequence of events that led up to the child’s death and receiving reassurance and bereavement support may reduce parental distress.
5. Allowing members of the psychosocial team to continue to provide support to the family and siblings. Families often indicate that they or their surviving children wanted to continue with “that social worker”

or “that child life specialist” rather than a new one.

6. Providing referrals to bereavement specialists in the community such as hospices, grief support agencies, *Compassionate Friends*, parent support groups, etc.
7. Offering psychoeducation about the potentially prolonged nature of grief for bereaved parents and siblings.
8. Continuing engagement with the family, when possible, for an extended period of time after the child’s death. This can include annual memorial events, letters on anniversaries, phone calls.

### CHALLENGES TO PROVIDING HIGH QUALITY CARE TO THE FAMILY

Despite the ethical duty to care for families in pediatric palliative care, physician response can be highly variable.<sup>5,28,29</sup> This variability may be attributable to several factors, including lack of training, growing demands for expansive care, discomfort in providing mental health/bereavement services to families, and reimbursement models that do not support such comprehensive care. In recent studies, physicians have reported a lack of comfort and confidence in providing pediatric palliative care, specifically as it pertains to psychosocial support.<sup>57,58</sup> PICU physicians reported that confidence and comfort increased as they practiced longer, but that the social and psychological needs of care remained areas that they did not feel as comfortable providing.<sup>57</sup> Palliative care physicians who provide

support to pediatric patients indicated moderate to high levels of discomfort with ethical issues related to pediatric palliative care.<sup>58</sup> In general, physicians reported that their level of training was inadequate to prepare them for pediatric palliative care, especially as it relates to supporting families, talking with siblings, and participating in decision-making.<sup>57,58</sup> These findings highlight the importance of increased training and support for physicians in pediatric palliative care and interprofessional education.

Although physicians are not expected to be experts in mental health or bereavement, their duty is to provide compassionate support based on current practice standards and to engage the members of the transdisciplinary team to assist them in this care. However, it can still be difficult for physicians to provide uniquely tailored, culturally appropriate, holistic, comprehensive, coordinated, long-term care to all families. Given current reimbursement structures, hospital-based palliative care teams are challenged to provide care to those who are most acutely in need and may not be able to attend to the long-term bereavement needs of a family. This may require physicians and their multidisciplinary teams to identify strong community resources to supplement the services and support they can realistically provide. Even with these barriers, physicians can take a stance of reflective and collaborative practice that continually honors the family and child.

**TABLE 1** Key Considerations Regarding the Care of Families

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- Physicians have an ethical duty to care for the families of children who have life-threatening conditions.
  - Families report feeling abandoned by their health care providers after the death of a child.
  - Siblings have unique and often unmet needs both during treatment and in bereavement.
  - Transdisciplinary team members such as social workers, child life specialists, psychologists, chaplains, and nurses can play an important role in meeting the emotional and bereavement needs of parents and siblings.
  - These skills can and should be included in medical education.
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### CONCLUSIONS

Tending to family needs is an essential and ethical duty in providing high-quality comprehensive pediatric palliative care. Physicians can significantly decrease burden and enhance satisfaction by caring for the family along with the child, and they can do so supported by their interdisciplinary team members. Palliative care is best delivered in a team committed to family-centered care and open and reflective practice that builds on the ever-changing needs of families.<sup>36</sup> Families have an ethical claim to care by virtue of their child’s and their own suffering and vulnerability. Physicians can and should respond to that claim by compassionately listening to families, improving communication, and engaging in meaningful and shared decision-making in the context of the family (Table 1).

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