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What is This?
Professional Boundary Issues in Pediatric Palliative Care

Jane B. Jankowski, LMSW, MSB

Abstract
This article explores the hypothesis that when a child has a life-limiting illness, the interpersonal boundaries between the patient, the patient’s parents, and the health care team members differ from traditional provider, patient, and parent boundaries because of the unique dynamics of palliative care in pediatrics. Providers from the Journey’s Palliative Care Team at Albany Medical Center completed a brief survey about working in pediatric palliative care and what ethical challenges they have faced in trying to maintain professional boundaries as new palliative care providers. A retrospective review of survey responses and a review of relevant literature offer insight into the various concerns reported by the Journey’s team. Conclusions about delivering comprehensive ethically sound palliative care services may serve as a pathway for future studies.

Keywords
ethics, professional boundaries, palliative care, pediatrics, end of life, multidisciplinary

Introduction
Historically, palliative care has not been associated with pediatrics. Advances in medicine over the past 50 years have “transformed childhood life expectancy throughout industrialized nations,” reduced infant and childhood mortality, and accordingly fueled a broad social perception that kids should not die. As noted in a 2002 editorial in palliative medicine, “deaths of children in the western world in the twenty-first century are perceived as unexpected, unfair, and overwhelming.” Accordingly, the development of pediatric palliative care services has lagged behind that of the adult palliative care services. Helen House, the first hospice for children, opened in the United Kingdom in 1982, well behind the initiation of the hospice movement in the United Kingdom in the late 1960s, with the establishment of the first modern hospice under Dame Cicely Saunders. The first hospice for children, Helen House, opened in the United Kingdom in 1982, well behind the initiation of the hospice movement in the United Kingdom in the late 1960’s. National Vital Statistics Report indicates that roughly 50,000 children died in the United States in 2010. In a social environment where children are expected to outlive their parents, the care of children with life-limiting illnesses has been one that tends to avoid the reality that children do in fact die. Recent legislation in the United States has opened the door to improving access to end-of-life care for children, with the passage of The Patient Protection and Affordable Care Act of 2010, permitting concurrent coverage of medical treatment and hospice services. Yet, gaps remain because “children in hospice must have a prognosis of 6 months or less,” and as children live longer with serious illnesses, this qualifying prognosis serves as a barrier to aggressive symptom management for kids who have longer life expectancies. Pediatric palliative care services are evolving to meet these needs.

The desire to foster nurturing, collaborative, and trusting relationships with patients and their families may require modification of the provider’s professional role in order to provide this holistic level of care not only to the patient but also to the entire family often in the home setting. This inclusive model may challenge previously understood social schemas and expectations in the doctor–patient–parent triad. The intensity of emotion surrounding the care of a child with complex life-limiting health problems affects the entire family constellation, and few medical specialties have the range of services under 1 umbrella to address the scope of needs presented in such cases. Multidisciplinary palliative care services specifically designed for pediatric patients strive to meet these needs; however, new teams like the Journeys Team at Albany Medical Center, which was less than 1 year old at the time of the survey, may include providers who have not previously participated formally in the palliative care programs and may find their professional boundaries challenged in new and unforeseen ways. Workers from various disciplines join together with families to provide comprehensive medical, psychosocial, and spiritual care to the

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children and their families, but competing pressures can emerge for the staff. Which actions represent a merging of interpersonal skills in end-of-life care and which actions cross therapeutic boundaries? How distant is too distant, and how close is too close?

Sheldon and Speck discuss translating clinical activities to the home setting, “can staff who have been trained and worked predominantly in the inpatient settings, but are now encouraged to work much more informally, manage the difficult boundary issues that arise when following up families in their own homes?” Guidelines for managing professional boundaries in this new context are few. Establishing and nurturing a therapeutic alliance requires creating a context, where patients can share and trust that a provider’s reactions will be contributions to a working relationship, not impacted by personal or social perceptions. In an article discussing the delivery of psychological services in the home setting, the authors Knapp and Slattery note that the American Psychological Association code of ethics “does not explicitly address accepting gifts, engaging in self-disclosure, or touching or hugging clients,” and practitioners are left to “wrestle with these dilemmas” when providing treatment. How are pediatric palliative care providers navigating the delicate balance of maintaining a professional role with the intimacy of serving children with life-limiting illness? Exploring the existing literature related to professional boundaries and comparing these findings to survey answers from the newly formed Journey’s Team will aim to define the kinds of boundary issues that arise in providing palliative care to children. The hypothesis of this project is that the kinds of professional boundary challenges that are found caused ethical dilemmas for these providers.

Methods

The primary intent of this survey was to provide insight for team leaders about internal quality assurance and training needs for Journey’s team members. The results were found to be worthwhile and prompted further exploration of the topic of boundaries in the pediatric palliative care arena. This study was reviewed and approved by the Albany Medical Center Institutional Review Board as a retrospective study of the original survey results.

The brief questionnaire was made available online to interested members of the pediatric palliative care team at Albany Medical Center Children’s Hospital, who were actively engaged in providing direct service to patients and families as members of the Journey’s Palliative Care Team. Five (n = 5) responders, representing the 4 target disciplines of medicine, nursing, pastoral care, and social work, completed the survey. Participation was voluntary and not compensated. In all, 2 respondents were physicians; 1 was a registered nurse, 1 was a social worker, and 1 was a chaplain.

The survey itself consisted of 8 questions and began by asking the responder to identify his or her profession and define his or her role in the team. Next, the responder was asked to indicate any observed boundary differences between his or her roles with the Journey’s Team when compared to his or her other professional roles. Additional questions asked the responders to identify specific challenges to their professional boundaries, whether their professional code of ethics addresses boundary issues, and how they have coped with these challenges. Finally, responders were asked what professional boundary issues they anticipated in the future.

A search of the relevant literature on the subject of “professional boundaries” was performed using 4 academic databases, Academic Search Elite, Medline, PubMed, and CINAHL, seeking peer-reviewed articles published between 1985 and 2012. Results from these searches were reviewed for relevance to the target professions and pediatric palliative care.

Results

Literature Review

The subject of professional boundaries has been addressed in the academic literature across many disciplines, and a number of themes emerged. Prohibitions related to sexual misconduct, financial relationships, maintaining privacy, and acting in manner that upholds the well-being of the patient are common, echoing themes dispersed among various professional codes of ethics. Although there is agreement about what is permissible in typical provider–patient relationships, there is also support for the hypothesis that the provider–patient–parent relationship differs in some key ways when (1) the patient is dying and (2) when the patient is a child.

When caring for patients who are dying, there are several contextual features of this relationship, which may increase susceptibility to boundary crossings. First, “the patient–physician relationship at the end of life often develops quickly and with considerable emotional intensity.” The intensity of this experience is not 1 sided, and providers “may experience a particular sense of closeness to their patients—increasing the chances that a boundary crossing may occur.” Second, the clinical encounter may occur in the home. Knapp and Slattery suggest that delivering home-based services requires special attention because “the (home) setting makes it more likely that other boundary crossings will occur and take on greater significance.” The informality of the home setting can provide patients and families with “more opportunities to challenge boundaries” and workers may “appear to assume the role of guests.” Third, the impact of being present during unrelieved suffering may have a cumulative effect on the workers, which may affect professional boundaries. In Braeden et al’s study of how providers cope when working with patients who have refractory suffering “there appeared to be a line in the sand beyond which they did not venture,” suggesting the importance of maintaining a clear emotional boundary. In this study, the findings suggest that boundaries may be crossed for therapeutic purposes with “careful discernment, experience, and wisdom” on the part of the practitioner.

When the patient is a child with life-limiting illnesses, the best interests of the child intertwines with the needs for both the
child and the family. The same intensity at the inception of the provider–patient relationship seems likely, but necessarily involves the child’s family. The American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care summarizes the scope of care provision by Palliative Care services noting that “the needs of families must be attended to both during the illness and after the child’s death to improve their ability to survive the ordeal intact.”

The goal of holistic family-centered care may generate a context ripe for boundary questions, partly out of the beneficial efforts to maintain collaboration with parents in order to “reach optimal outcomes and safe passage for the child.” Whaite suggests that boundary confusion may occur when a provider becomes overinvolved, and relationships extend outside the health care setting, when a provider gives gifts to the child or the family, joins in shared meals, and attends funerals. However, Whaite challenges the notion that such boundary crossings are problematic and suggests that this “openness and sharing” dissolves barriers and allows for improved therapeutic boundaries. Doherty et al surveyed providers about experiences with pediatric palliative care and found that “boundaries get crossed in time and time again” creating strain for staff members and suggesting the need for a reevaluation of professional boundaries for pediatric palliative care providers.

Survey Results

Formed in 2011, The Journey’s Team at Albany Medical Center Hospital in Albany, New York consists of physicians, nurses, social workers, chaplains, ethics consultants, a pharmacist, and an administrative coordinator. The core team actively involved in providing patient and family care consists of a chaplain, nurse, and physician for most contacts. Although the team consists of experienced professionals, few had ever worked in a formal palliative care setting prior to joining the Journey’s team. The staff members serving in the Journey’s team provided confidential responses to questions about professional boundaries. Roles were defined by each professional. Physicians (n = 2) identifying themselves as team leaders responsible for the medical management of cases, identifying potential referrals, and ensuring follow-up care is completed by medical colleagues. One nurse (n = 1) indicated having responsibility for coordination of services, providing staff education, and working as a liaison between medical providers, families, and community resources. A chaplain (n = 1) reported having the responsibility of helping patients and families through emotional and spiritual suffering, and one team social worker (n = 1) defined this role as one which focuses on coordinating concrete psychosocial needs and providing some counseling services.

When asked to compare the professional boundaries established with patients in their normal day-to-day professional work with that of the pediatric palliative work, respondents reported that the work with the palliative care service required either the same or more flexible professional boundaries. Respondents were split based on whether their professional code of ethics addressed boundary issues, with half indicating their code did include this guidance and half answering “no” or “unsure.” When faced with needing support in managing boundary concerns, respondents were asked to check all strategies they have employed. Most reported managing the problem alone, seeking advice from a trusted peer, or finding outside support.

Open response questions asked a variety of questions about professional boundaries directly related to each professional’s personal experience working with the pediatric palliative care patients and families. One physician reported having had concerns about sharing her personal cell phone number with these patients and families, as this seemed to bend the typical parameters established to limit accessibility and distinguish private time from work time. This respondent reported managing these encounters by setting firm limits when someone abuses the privilege and by promptly triaging calls into those that can wait for office hours and those that cannot. This physician indicates that by declining patients’ cell phone requests for immediate assistance has not damaged these doctor–patient/family relationships. The social worker in the team reported that boundary issues arose when families viewed the social worker as a friend rather than as a clinical provider. The team chaplain asked “Just how involved do I get?” in reflecting on involvement in family life. Being approached for money to buy groceries or even bringing groceries to the house knowing the family cannot get out seemed to understandably stretch the boundaries of professional chaplaincy for this provider. Responding to invitations to gatherings such as birthday parties, fundraising events held on behalf of families with ill children, and family functions were boundary-related challenges noted in the physicians’ and chaplain’s responses. The nursing professional indicated having boundary concerns related to the longer term relationship in the palliative care setting and feeling that the role falls into an undefined zone where the role is not very clear. This respondent wrote “I am still feeling my way around this grey area and trying to decide what is crossing the line and what is not.” The majority of respondents in this small sample indicated a need for “more flexible” professional boundaries when engaged in their work with the Journey’s team, which may be a reflection of this sense that the nontraditional setting is already stretching the workers’ professional boundaries.

When asked what ethical dilemmas had been encountered when providing pediatric palliative care, the respondents noted that gifts from patients/families posed dilemmas, because they felt it was awkward to accept or decline such gestures of gratitude in the context of these intimate provider–patient relationships. Handling “friend requests” from parents or patients on Facebook accounts were noted to be points of ethical concern, as this posed a similar risk of offending the patient/family because this interaction seemed to reframe the professional relationship as one of friendship in the social media context. Maintaining confidentiality became an ethical dilemma for one provider who was not sure how much detail about families’ lifestyles ought to be shared at clinical meetings, because it was not always clear how much the family issues affected the patient’s medical care. This provider was concerned that such
disclosures could alter perceptions of the family unit by either generating empathy or creating biases and damaging the existing relationships.

Limitations

The most significant limitation of this study is the small size of this survey. This poses 2 problems, the first being that the small size limits the degree to which any of the results can be generalized to pediatric palliative care providers outside of the Journey’s team at Albany Medical Center Hospital. The second concern is that the small number of completed surveys may make it easier to identify individual respondents. The survey instrument itself is not a validated tool and cannot be presumed to fully assess the respondent’s experiences. Expanding the number of participants to include providers in other programs, other regions, and even other counties would add substantially to the utility of data on professional boundaries in pediatric palliative care.

Discussion

The experiences of the Journey’s team highlight a range of professional boundary issues that pose ethical dilemmas for the providers, suggesting support for the hypothesis that interpersonal boundaries differ in pediatric palliative care when compared to other professional roles held by this small set of providers. Upon careful review of the brief survey responses, the nature of these dilemmas seems to be related to the intimacy required to provide comprehensive palliative care services while ensuring enough distance to “not threaten the neutrality of the professional relationship.”

The guidance available in the codes of ethics suggests that crossing professional boundaries causes a loss of objectivity due to “becoming deeply and personally involved with child and family.” Personalized, holistic, compassionate care for children in palliative care treatment programs seems to necessitate a close working relationship while navigating the delicate social norms without losing one’s ability to maintain a level of neutrality and professional distance. Flexible boundaries are not broken boundaries but nonetheless require clear limits.

Fostering an understanding of how the nontraditional setting can affect boundaries may help providers distinguish their role from that of a guest or friendly visitor during home visits. Maintaining one’s professional identity in a nontraditional setting may require some latitude in defining boundaries but seems to also demand an understanding of social roles within the medical context. Perhaps for palliative care providers, it is a more useful exercise to consider that how the provider’s “job is defined depends on the delicate play of intimacy and the distance that constitutes a boundary” rather than the boundary defining the job. Survey responses indicated questions about sharing meals with families and patients, as the family is likely acting out of politeness and perhaps with gratitude for the medical services being provided. Nonetheless, this social practice places the clinicians in the role of a guest, which is not how the clinician likely sees his or her role. Frequent interactions with caregivers may give the families the sense that members of the palliative care team are friends rather than friendly care providers with a finite purpose. One team member shared that after the death of a young patient, the primary caregiver expressed feeling like she had lost a friend, when the clinician’s daily phone calls to check on the patient ceased. The clinician viewed those calls as important fact-finding tasks to see how much medication had been required overnight, and whether or not supplies or visits were needed. Providing concrete assistance to families with seriously ill patients, such as helping with the grocery shopping and providing babysitting, which enables the primary caregiver to attend to personal appointments, are clearly outside the boundaries of clinical work and may represent a misuse of the palliative care provider’s time and energy, even when the need is genuine. Clinicians must consider the risks associated with the slippery slope of becoming involved in family life in ways that may contribute to role confusion. The important lessons learned here support the need to define the boundaries of the palliative care relationship in order to maintain a therapeutic clinical focus.

The therapeutic use of self can add to the provider–patient relationship, without confusing a deep commitment to patients with a loss of professional identity may offer additional options for managing professional boundary dilemmas. Literature and textbooks related to counseling services often refer to “the use of self” as a concept that allows the provider to be authentic and engaged in the therapeutic relationship without losing clinical focus. Defined as a latter step in the formation of a working alliance with clients, the provider may “increasingly use themselves as tools to facilitate growth and accomplishment” in the growing relationship. Genuine reactions and appropriate disclosure of impressions and experiences can build trust, though care must be taken to avoid self-disclosure, which is for the clinicians’ benefit. Given the uniquely intimate relationship that forms between patients/families and palliative care providers, it seems fitting to consider how the individual provider contributes to the clinical context simply by being themselves and remaining self-aware. Understanding how the self plays a role in defining the relationship may be an important part of future training for palliative care team members who will inevitably face boundary issues in their practice. Avoiding pitfalls such as sharing personal problems, keeping secrets with the patient/family, believing no one else can meet the patient’s needs, or spending more time with favored patients/families require self-awareness as well as a mechanism for seeking supervision to manage these boundary crossings should they occur. Learning to be self-aware and effectively incorporate self-knowledge can allow the provider to blend their authentic self with their professional persona, without becoming overinvolved or underinvolved and enhance the working relationship with patients and families.

Conclusions

The results of this survey and literature review seems to suggest that further research about professional boundary issues for pediatric palliative care providers is warranted to understand
and improve these relationships. Although the survey group was small, the dilemmas faced by the Journey’s team are not likely unique to this group, given the similarity of survey responses and those presented in the existing literature. Providing care in nontraditional settings such as the home, offering 24-hour access to clinicians, sharing cell phone numbers, and coping with the psychosocial issues related to life-limiting illness forge a unique intimacy that need not be sacrificed for the sake of maintaining professional boundaries. Instead, integrating communication about boundary limits into what is being discussed about the scope of services may help families view the palliative care workers’ role realistically as well as give the providers a point of reference when professional boundaries are challenged. Encouraging palliative care professionals to develop the self-awareness needed to recognize when they may be justified in stretching a boundary or when their objectivity may be at risk is another avenue to help avoid the pitfalls of professional boundary violations. As pediatric palliative care grows and matures as a field of practice, future research may be useful to better understand the unique relationship between providers and families caring for medically fragile children.

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