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Death and dying, ethics, pediatric end-of-life care

ABSTRACT

The death of a child may have a profound impact on parents, family members, and health care providers who provided care for the child. Unique challenges are faced by parents of seriously ill children as they must serve as the legal authority for health care decisions of children under age 18, although the child's wishes must also be considered. Social workers must balance core social work values, bioethical values, and psychosocial issues presented by such situations. While studies have been conducted with physicians and nurses regarding ethical issues in pediatric end-of-life care settings, little is known about how social workers experience these conflicts. This article utilizes two vignettes to illustrate potential ethical issues in this setting and applies the National Association of Social Workers Standards for Palliative and End of Life Care (NASW, 2004) to explore options for their resolution. These vignettes provide descriptions of possible reactions in this setting and can be used as a basis for further exploration of ethics in pediatric end-of-life care from a social work perspective.

Despite advances in medical technology that have extended the human life span, thousands of children die in the United States each year. In 2011 there were approximately 62,100 deaths of children and young adults under the age of 24 (Hoyert & Xu, 2012). While sudden and violent deaths are more com- mon in the 14- to 18-year-old range, conditions for which palliative care is more often sought are more frequent among younger age groups. For instance, in 2011 congenital anomalies and conditions related to gestation and low birth weight were the leading causes of death in children under 1-year old, and congenital malformations and cancer were among the top three causes of death in children ages 1 to 14 years (Hoyert & Xu, 2012).

The death of a child may have a profound impact on the family. The grief of bereaved parents has been documented to be more intense and long-lasting compared to other groups of grievers (Kersting, Brahler, Glaesmer, & Wagner, 2011; Leahy, 1992–1993). Parents may show a wide range of grief reactions and experience a unique grief trajectory in which emotional equilibrium is not regained for years after a child dies (Clayton, Desmarais, & Winokur, 1968; Klass, 1997; Rando, 1985). Due to the high emotional intensity involved, working with children and families at the end of life requires great sensitivity and attention to ethical concerns by all providers involved, including social workers.

The purpose of this article is to use vignettes reported by practicing MSW- level social workers (through MSW student interviews) to identify ethical challenges and implications related to caring for children near the end of life and their families, and to explore how standards published by the National Association of Social Workers (NASW, 2004) can be used to illuminate ways to resolve potential ethical tensions in this context.

Literature review

The provider's role in helping parents

Social workers have the opportunity to offer compassionate care and support to patients and families that can help facilitate healing during a child's illness and after his or her death. After the death of a child, parents consistently reported that the quality of communication and support provided helped to shape their experience of diagnosis, treatment, palliative care, and follow-up services (Aschenbrenner, Winters, & Belknap, 2012; Hsiao, Evan, & Zeltzer, 2007). Sharing problems with someone during a child's illness was associated with a greater degree of loss resolution among parents whose children had died of cancer many years earlier (Kreicbergs, Lannen, Onelov, & Wolfe, 2007). Parents appreciated when providers built relationships with the patient and family and were available when needed; communication was open, honest, and direct without the perception that the provider was trying to take away their hope for their child; full information was provided; providers prepared them for bad news; and their input as parents was valued (Aschenbrenner et al., 2012; Contro, Larson, Scofield, Sourkes, & Cohen, 2002; Hsiao et al., 2007). In another study, the expression of compassion by providers from diagnosis to death emerged as a key theme among bereaved parents (Cacciatore, Thieleman, Lieber, Blood, & Goldman, In press). However, even a single negative interaction may have a lasting impact (Contro et al., 2002). Parents frequently reported a lack of adequate information, poor or insensitive communication with providers, and inadequate support from the health care team, as well as the need for improvements in pediatric hospice services (Aschenbrenner et al., 2012; Contro et al., 2002). The perception that a child received inadequate symptom relief and suffered at the end of life was noted to haunt parents for months and years after the death (Contro et al., 2002). Social workers, with their knowledge of a variety of influences on human behavior and an emphasis on client- and family-centered care, can help provide the psychosocial support that children and their families need to avoid causing additional suffering in an already intensely difficult situation.

Shifting the focus from cure-oriented treatments solely to palliative measures is an emotionally painful process for patients, their families, and the health care team. The imminent death of a child may represent the ultimate failure of modern medicine (Jacobs, 2005). Parents may have difficulty believing a child will die and may understandably hold onto hope that the child will live after the health care team has discussed with them that long-term survival is not possible (Hinds et al., 2005; Wolfe et al., 2000). Good, clear, consistent communication is essential so that parents do not feel that the health care team has “given up” on their child, which makes discussions about end-of-life care more difficult (Hinds et al., 2005). Thus, working with parents of children with life-threatening conditions requires sensitivity, compassion, and empathy.

Difficult decisions involving children at the end of life

Decision-making may be complicated when working with children with life- threatening conditions due to their inability to provide consent. Because children do not have the legal authority to provide informed consent for health care decisions, parents or legal guardians must offer informed consent on their behalf. Ideally, children will also offer informed assent to such decisions. However, ethical issues arise when children and their parents are not in agreement with a decision, such as to pursue or forego further treatment (Freyer, 2004). In cases in which a child's opinion will not change a decision, this should be disclosed to the child to avoid engaging in deception and violating the principle of justice (Kunin, 1997).

While children under 6 years are often assumed to lack the capacity to make informed choices, older children are able to state preferences (Jacobs, 2005). From about the age of 12 to 14 upward, children may have functional capacity (Freyer, 2004; Jacobs, 2005), often understood as the ability to under- stand the nature of death, to reason, to understand relevant information, to choose one course of action over another voluntarily, and to appreciate of the gravity and permanence of decisions (Freyer, 2004). However, even younger children may have preferences about their care and should have their wishes considered whenever possible (Freyer, 2004; Kunin, 1997). Children as young as 9 years old may be able to make reasonable decisions about treatment and their personal experience with an illness can enhance their under- standing of it (Kunin, 1997). Younger children can be considered to have "autonomy of thought and feeling" (Kunin, 1997, p. 45), if not autonomy of action, which requires that clear explanations be given in language children can understand and that they are given as much control as is developmentally appropriate (Freyer, 2004; Kunin, 1997). The developmental needs of the child must be considered in each case. For instance, the effects of treatment may interfere with typical adolescent development in the United States, including the process of gaining greater independence from parents (Freyer, 2004), and must be considered by the treatment team.

Like their parents, children with life-threatening conditions will hope for a cure, though they tend to adjust their hopes as their prognosis worsens and may focus on hopes related to not suffering or for their family's comfort and well-being (Foster, Lafond, Reggio, & Hinds, 2010). However, providers may avoid talking about hope when it is clear a child's life cannot be saved, making a difficult situation even harder for patients and families (Foster et al., 2010). Providers may also delay discussions about end-of-life decisions due to their own discomfort, resulting in pressure to make decisions in the hours before a child dies (Hinds et al., 2005). This may increase the stress of the situation and complicate parents' ability to spend their last hours with their child as they desire.

Some of the most difficult decisions children and parents face are those related to end-of-life care, such as whether to withdraw or withhold life support measures (Aschenbrenner et al., 2012; Foster et al., 2010; Hinds et al., 2001). Though physicians are not required to initiate or continue treatments that offer little to no benefit (Jacobs, 2005; Truog et al., 2008), lack of knowledge about ethical standards may contribute to difficulties related to withholding or discontinuing treatments. In a survey of nurses and physicians in a variety of specialties, many respondents were uninformed about published ethical recommendations, yet still rated themselves as "ethically knowledgeable" (Solomon et al., 2005). Despite consensus that withholding and withdrawing treatment are not fundamentally different, some respondents believed the two measures to be ethically distinct. Many believed that artificial food and fluids must always be given, even when other forms of life support have been discontinued (Solomon et al., 2005), though such measures are not legally or ethically required (Truog et al., 2008). Additionally, some respondents believed it was illegal to give sufficient pain relief if it might has- ten death. However, this is quite rare and there is consensus that efforts to relieve pain are justified even if they may result in the unintended but perhaps foreseen hastening of death (Truog et al., 2008). Many respondents also reported that children at their institutions are often not provided adequate pain relief and many believed this was because of fear of hastening a child's death (Solomon et al., 2005). Undoubtedly, provider uncertainty in these ethical areas may have a negative impact on children and their families.

Knowing that all curative approaches have been tried is essential for parents in order for them to make informed end-of-life decisions (Hinds et al., 2001). Parents often review the decisions made for their children and try to assess if they were "good" parents (Foster et al., 2010). This often entails the need to act with full information in the child's best interests; be emotionally and physically present for a child; express love and affection, prevent suffering and promote health when possible; and advocate for a child (Foster et al., 2010). The weight that parents give to each of these aspects may influence whether they will seek continued cure-oriented treatment or palliative measures to increase comfort for a child when death seems imminent (Foster et al., 2010). Strong relationships with providers may help parents recognize that they were, in fact, “good” parents, even when all their efforts to save a child’s life are unsuccessful.

Ethical dilemmas for health care providers

End-of-life decisions are readily recognized as directly affecting children and their families; however, such decisions may also affect health care providers, who often form attachment bonds to their patients and grieve when they die (Doka, 2005; Jacobs, 2005). Health care providers often experience concerns of their own conscience, particularly related to the use of overly burdensome treatments that offer few benefits, and may have difficulty making sense of the impact of treatment choices on children, particularly when choices are in conflict with personal beliefs (Jacobs, 2005; Solomon et al., 2005). In one survey, over one-half of the professionals sampled reported having acted against their conscience when caring for children (Solomon et al., 2005). Conversely, respondents generally did not feel they were giving up on cure-oriented treatment for children too soon. Thus, providing overtreatment was a larger concern to providers than providing undertreatment; such concerns are more prevalent in pediatric compared to adult end-of-life care settings (Solomon et al., 2005). Team members may also feel left out of important decisions that affect patients and can result in compassion fatigue, especially if there is no institutional support for their own grief after the death of a patient (Doka, 2005).

National association of social workers’ standards for palliative and end of life care

Due to the unique factors associated with the illness and death of a child, it is not surprising that ethical dilemmas may arise in this context. Many health disciplines have published guidelines for providing care in these settings. Social workers in palliative care and indeed all NASW members and students are required to adhere to the *Code of Ethics* (NASW, 2008). It emphasizes meeting the basic needs and enhancing the well-being of all individuals with special attention to vulnerable populations such as children. The NASW Standards for Palliative and End of Life Care (NASW, 2004) provide additional guidance to social workers dealing with end-of-life issues. These standards include nine practice areas: (a) ethics and values; (b) knowledge; (c) assessment; (d) intervention/treatment planning; (e) attitude/self-awareness; (f) empowerment and advocacy; (g) documentation; (h) interdisciplinary team- work; and (i) cultural competence, as well as two professional preparation and development areas: (j) continuing education; and (k) supervision, leader- ship, and training.

Ethical principles are a core component of these standards and defined by the NASW (2004) to include: justice (fair treatment), beneficence (doing good), nonmaleficence (not causing harm), understanding and tolerance (being able to see alternate points of view), publicity (the recognition of standards and acting in accordance with them), respect for the person, universality (taking actions that hold in all situations), veracity (honesty), autonomy, confidentiality, equality (seeing everyone as morally equal), and finality (action that overrides other demands and customs). Bioethical and legal considerations—including proxy decision-making, withholding or with- drawing treatment, and the right to refuse treatment (each defined further within the standards)—are also recognized as relevant to ethical decision- making at the end of life, though doctors, social workers, and other health care professionals must also adhere to bioethical principles regarding medical decision-making. For instance, Kunin (1997) identified four key ethical concepts in pediatric end-of-life care: autonomy, beneficence, nonmaleficence, and justice.

Knowledge of child development and understanding how to involve children in age-appropriate ways is essential in end-of-life care (NASW, 2004). Assessment is crucial for determining a child's level of understanding and desire for autonomy in the context of illness, with attention to cultural factors that may influence the family's hopes, attitudes, and beliefs about matters related to dying. Thorough assessment will help shape treatment planning that may focus either on cure-oriented or palliative-oriented medical treatment, as well as psychosocial interventions to improve the well-being of the child and family. Interventions and treatments provided should enhance the client's decisions and abilities. In this context, the provider's attitude and self-awareness are important considerations. A provider must take an attitude that embodies sensitivity, compassion, and respect for clients' dignity and self-determination. Self-awareness should center on the provider's own feelings, values, and beliefs, as well as how these aspects may influence the care they provide.

Empowerment and advocacy on behalf of a client should also be foremost in practice in this setting. The use of appropriate documentation can help improve communication among all providers involved and avoid the kind of negative interactions known to be harmful to families of children in end-of-life settings. Because social workers often serve as liaisons between family and medical systems, they are an important component of the interdisciplinary team. In this capacity, social workers can help reinforce relationships between clients and medical providers with the well-being of the client in mind.

Maintaining relevant continuing education hours and seeking supervision, leadership, and training are also pertinent pieces to providing competent ethical care with pediatric patients at the end of life (NASW, 2004). Death education in social work programs is commonly offered through elective courses and may be omitted from core courses (Walsh-Burke & Csikai, 2005). Social work students may not feel prepared for ethical issues in end of life situations (Csikai & Raymer, 2005), which can lead to potential burnout or compassion fatigue. Recognizing and addressing the professional and personal challenges of health care providers has been identified as a core component of training for those working in pediatric settings (Sahler, Frager, Levetown, Cohn, & Lipson, 2000). On-the-job training is important and strategies such as mindfulness may help providers regulate emotions and improve psychological well-being, reducing the risk for compassion fatigue and burnout (Cacciatore, Thieleman, Killian, & Tavasolli, 2014; Thieleman & Cacciatore, 2014).

Vignettes

To elucidate ethical issues related to caring for children nearing the end of life and their families, two vignettes are presented as told to MSW students by social workers practicing in pediatric end-of-life care settings. The two vignettes were obtained from a master's-level student assignment that required students to interview practicing MSW-level social workers about ethical dilemmas faced in practice as part of an online social work ethics course. The purpose of the assignment was, first, to learn about real world ethical dilemmas, and, second, to apply and discuss course concepts in order to prepare students for social work practice. Here, the first portion of the assignment is utilized, in which students provided a description of ethical challenges faced by the social worker they interviewed, including answers by the interviewee to the questions posed according to the semi-structured interview schedule. The schedule instructed students to ask the practitioners to (a) describe an ethical dilemma experienced in social work practice, (b) describe how they responded to the dilemma, (c) describe how their training and values affected the decision-making process, (d) discuss whether aspects of diversity (e.g., gender, religion, culture) were involved in their decision-making process, and (e) describe what aspects of the situation were the most difficult for them.

Students were instructed to interview someone who held a master's degree in social work (with MSW, LMSW, or LCSW credentials) and at least 2-years post-master's experience in the field. All interviews were conducted in-person by the student at a location convenient to the interviewee. Interviews were not audio recorded, and this may have affected student recall of information given in the interview and is a limitation of this source of information. Students were instructed about how to conduct interviews using semi-structured inter- viewing, including that all questions should be asked while soliciting as much information as possible to understand the context of the situation via the use of additional open-ended prompts (e.g., "Can you tell me more about that?"). Students were instructed to provide a description of the job of the social worker interviewed and their credentials while being careful not to reveal any names or agency affiliations, as well as to post the answers to the semi- structured interview questions in a discussion board post for other students to view and discuss as a second part of the assignment.

A total of 43 student assignments reporting completed interviews were collected; representing various fields of practice. Approximately 20% (*n* ¼ 8) centered on issues related to death and dying. Of these eight, two focused on pediatric patients. The source of the data limits the understanding of the scope of social workers' involvement in each of the dilemmas presented given the nature of the class project and the use of secondary data that was not originally conceptualized as a research project. However, the vignettes portrayed examples of the challenges related to providing ethical care in end-of-life contexts and the instructor believed that these could be useful for social work education and practice. Approval to use the de-identified student interview assignments was granted following the conclusion of the class by the university's Institutional Review Board. Identifying details, such as names and places of employment, were replaced with pseudonyms by the student to protect the anonymity of the parties involved.

Vignette 1: "Exhaust all measures"

Nick was a 10-year-old boy with a rare and high-risk stage III sarcoma on his femur. For 1 year, Nick's treatments included 4 cycles of neoadjuvant chemo- therapy to shrink the cancer, surgery to remove the sarcoma and infected bone, and another 2 cycles of adjuvant chemotherapy to kill remaining cancer cells followed by several rounds of radiation along his thigh. He was discharged home and experienced a short period of remission. At his 6-month check-up, a body scan showed that the cancer had metastasized to his lungs. Nick's family was devastated. He was re-admitted to the inpatient cancer unit, where Margaux, a licensed clinical social worker at the hospital's Pediatric Oncology Unit, helped facilitate a meeting between Nick's family and his oncologist. The oncologist informed Nick's parents that there were no other options that might cure his cancer and suggested palliative care to keep him comfortable. Nick's parents were shocked and could not believe their son would die. They wished to be seen by a new oncologist and requested that the hospital "exhaust all measures" to save their son.

Nick's doctor asked Margaux to meet with his family to explain that additional treatment would not save his life and that palliative care measures could help improve the quality of his remaining time. Nick's parents still could not believe he would die and expressed a desire for continued cure- oriented treatment. The parents, who identified as Catholic, believed that God wanted them to fight for their son and requested more chemotherapy and radiation. Margaux realized that Nick's parents were unable to focus on anything other than their hopes for cure in the treatment for their son. Instead of trying to change their minds about cure-oriented treatment, she listened while they expressed their anger and frustration, reassuring them that their feelings were normal. Margaux, a parent herself, empathized with the parents but also saw how weak and exhausted Nick was from the treatments. It seemed cruel to her to put Nick through treatments that would not prolong his life and might actually hasten his death due to his weakened condition.

When Nick's parents and doctors were not able to reach consensus about treatment, Margaux took the case to the hospital ethics board. The board reviewed Nick's records, interviewed the parents and doctors, and ultimately supported the treatment team in offering palliative care and refraining from providing cure-oriented treatments. Eventually, Nick's parents came to the realization that nothing could save their son's life. They took Nick home so he could die surrounded by the people who loved him. Margaux reflected on how difficult it can be for parents to recognize the fact that a child will die and on the challenges related to helping them understand the situation when there is no cure.

Vignette 2: "Don't give up on me"

Lauren was diagnosed with leukemia at 12 years old. Her cancer was aggressive, yet she remained hopeful throughout nearly three years of treatment and two remissions. Her leukemia returned within three months of the last remission. Lauren was too weak for a bone marrow transplant and, at age 14, had no further cure-oriented treatment options. Lauren's parents had watched their daughter deteriorate physically. They understood the grave situation and felt that treatment was doing more harm than good. Lauren was referred to in-home hospice care under the supervision of Pam, a licensed clinical social worker and experienced end-of-life caregiver. Lauren, who had always been active in her medical care, had a difficult time with the news that there were no further cure-oriented measures available to her. She remained close to her oncologist, Dr. Seaborne, after the hospice referral. She pleaded with him, "don't give up on me," insisting on receiving treatment to boost her white blood cell count. Dr. Seaborne acquiesced to Lauren's requests even though the transportation and procedures caused significant pain and made her weaker.

Lauren's parents came to Pam feeling frustrated. They could not under- stand why Lauren was able to successfully request care that would do little to extend her life and would instead cause discomfort. They suspected that Dr. Seaborne's actions were motivated by his closeness with Lauren and not a belief that the treatments were beneficial. Though Lauren was receiving hospice care, she was not ready to sign a do not resuscitate (DNR) order and continued her pleas for more treatment. The medical team and Lauren's parents disagreed but wanted to honor her wishes. Providers agreed not to pressure Lauren into signing a DNR order with the understanding that her parents, who had decisional authority, planned to sign a DNR order once Lauren was unable to voice her wishes. Lauren, however, believed that efforts would be made to resuscitate her. She was alert, oriented, and decisional within minutes of death and died rather suddenly at home. Lauren's parents recognized her condition was terminal and did not pursue any form of resuscitation, relying instead on the support of hospice providers.

Discussion of vignettes

These two vignettes depict two examples of how social workers may be involved in caring for dying children their families, including their role in identifying and addressing ethical tensions. In this section, the two vignettes are discussed in reference to the NASW

Standards for Palliative and End of Life Care (NASW, 2004) and recent research presented in the literature review. The goal is not to specify the resolution of ethical tensions, but rather to identify important factors related to each case and potential alternative courses of action for ethical tensions that emerged. Each of the authors drew on their shared practice experience, which includes experience with pediatric patients and their families in hospice and palliative care settings; working with bereaved parents after the death of a child; in child and family social work practice settings; as well as teaching MSW-level ethics courses, to discuss interpretations of the vignettes, and to provide recommendations for practice and education.

Ethics and values

In both vignettes, the social workers appear to have demonstrated respect for persons and the health care teams appear to have cared deeply about the well-being of the children they were treating. For instance, Lauren's parents, hospice providers, and the medical team welcomed her active involvement in her care and did not pressure her to sign a DNR order even as her health status was deteriorating. Nick's social worker demonstrated a commitment to understanding and tolerance for alternate viewpoints and religious views, holding several meetings with Nick's parents and treatment team to facilitate communication and discuss options for care, allowing his parents to vent their frustrations over their son's care and deteriorating health. In both vignettes, it seemed that the social worker communicated in ways that conveyed compassion, empathy, sensitivity, and respect. However, the quality of communication between these children and their families and the various health care professionals is not known. While honest and empathetic communication is not a guarantee that conflicts will be avoided or easily resolved, it is imperative in providing competent care and is a key factor in shaping perceptions of care (Aschenbrenner et al., 2012; Freyer, 2004). Ensuring that everyone on the interdisciplinary team has information from other team members and is engaging in clear communication may help improve communication with children and their families and reduce the potential for ethical dilemmas.

Despite the teams' best efforts, tensions involving ethical principles may arise, given the complicated and emotional nature of working with children in end-of-life care settings. Both of these vignettes illustrate tensions between autonomy, beneficence, and nonmaleficence. Matters of autonomy are complicated when dealing with children because they do not have the legal authority to provide informed consent for health care decisions and their parents or other legal guardians must make decisions on their behalf while honoring their wishes whenever possible (Freyer, 2004). Respect for the autonomy of Nick's parents, acting in the best interests of their child, had to be weighed against concerns about providing only treatments with a reasonable possibility of benefit and avoiding overly burdensome treatments that offered little benefit. There is no reason to believe that Nick's parents wished for him to experience additional pain without significant benefit in asking for further treatment; parents of children with life-threatening conditions are assumed to be acting with beneficence and nonmaleficence unless there is evidence suggesting otherwise (Kunin, 1997). Health care providers in both scenarios were in conflict, either internally or with the patient or family, as to whether to offer continued treatment that would likely be ineffective. This resonates with a previous finding that providers tend to experience a high degree of moral conflict around the potential for the overtreatment of children (Solomon et al., 2005).

The tensions that emerge when parents and health care providers disagree about the best course of action for end-of-life care call for attention to the ethical principle of understanding and tolerance. In Nick's case, both parents and providers were presumably advocating for the best interests of the child as they understood them, though they likely had different priorities. While the treatment team may have been trying to avoid unnecessary pain without hope of significant benefit through further treatment, Nick's parents were likely struggling to come to terms with the inevitability of their son's death and were desperate to "exhaust all measures" that might prolong or save his life. Validation of their efforts to be "good" parents (Foster et al., 2010) may have helped improve communication and reduce conflict. However, because prognosis is often uncertain in children, it is difficult to determine when cure-oriented measures will convey more burdens than benefits. While the concurrent provision of curative and palliative measures can offer many benefits, it may also contribute to this uncertainty (Hinds et al., 2005). Thus, respect for different viewpoints and the recognition that both Nick's parents and treatment team were attempting to act morally is imperative.

Ethical issues can also arise when children and their parents are not in agreement with a decision, such as to pursue or forego treatment (Freyer, 2004). This possibility cannot be assessed in the first vignette, in which Nick's wishes and the extent to which they may have influenced his parents' actions are not known. However, there was clearly conflict between what Lauren desired and what her parents preferred. Lauren, who was older than Nick, had been kept informed of her condition and results of treatment over time and likely had the functional capacity to understand the situation and her options as well as their consequences. Respect for her autonomy was tempered by the recognition that the treatments she desired could not provide the effect she wanted (a cure) and were causing her further physical pain. While the team initially honored her wishes for continued treatment, they ultimately acted in accordance with her parents' wishes, who had the legal authority to provide consent in not pursuing resuscitation. However, additional ethical concerns and questions emerge from this situation: was the treatment team complicit in deceiving Lauren about her code status by agreeing to honor her wishes to be resuscitated with the knowledge that her parents would step in and consent to a DNR order? Did this course of action conflict with the ethical principle of veracity? Was this course of action fair to the child? What kind of impact did this situation have on her parents and their subsequent grief? Which ethical values should be given priority when there is a conflict? As in many ethical matters, there is often no clear "right" answer.

Knowledge, assessment, and cultural competency

Both vignettes have implications for the areas of knowledge, assessment, and cultural competency. For instance, Lauren was involved in her own care and seemed to have a good understanding of her situation overall, at least until she approached death. However, perhaps further efforts could have been made to assess her understanding of death and her prognosis once it was clear her illness could not be cured. This might have avoided a situation in which a child was provided treatment of little to no benefit and in which her parents and treatment team were not completely honest with her about how far they would go to try and keep her alive.

In Nick's case, efforts toward cultural competency included attempts by the social worker to understand and honor his family's spiritual beliefs even though their decision to continue cure-oriented treatment was in conflict with ethical standards relating to concerns of beneficence and nonmaleficence, or acting for good and avoiding causing harm. It is not known whether the treatment team drew upon the family's religious resources in addressing the ethical dilemma regarding Nick's treatment. Including cultural and spiritual factors in an assessment can provide context to a family's goals and wishes for care, and cultural competency includes understanding the culture of an individual family system and how families operate in decision-making. Though being cured from cancer was clearly the desired outcome in both vignettes, social workers should assess for secondary treatment goals such as symptom reduction, the pro- vision of excellent care in the patient and family's setting of choice, and involving children in their care decisions at a developmentally appropriate level. In cases in which a child's life cannot be saved, these may become the primary goals.

Treatment planning, interdisciplinary teamwork, advocacy, and self-awareness

The vignettes described also illustrate examples of treatment planning, inter- disciplinary teamwork, advocacy, and self-awareness. In Nick's case, the social worker attempted to negotiate conflicts between the family's wishes for cure- oriented treatment and the health care team's recommendation for palliative care and made a referral to the hospital ethics board. Though the use of ethics committees is recommended as part of a process-based approach for end-of- life conflict resolution (Truog et al., 2008), can provide an opportunity to engage the family in joint decision-making, and may have been the best intervention in this case, it can result in feelings of powerlessness or a sense of having been left out of the process (Doka, 2005). It is also possible that the ethics board referral resulted in a breakdown of trust and additional regrets in an already painful experience for Nick's parents, though their responses to this action are unknown. While the vignette noted that Nick's parents eventually realized treatment could not cure their son, whether this realization occurred in the context of ongoing support from the treatment team and the extent of any follow-up care remains unknown. Ideally, support and dialog with Nick's parents would have continued well beyond the death of their son, given the profound impact of the death of a child on the family.

Likewise, the extent of communication by Nick's parents and providers with him about his condition, prognosis, and care options are unknown. Was he kept informed, at a developmentally appropriate level for a 10-year- old, throughout his illness? Did his parents or the treatment team have an honest discussion with him about his situation? What were his own concerns and preferences? The answers to these questions could provide additional context and perhaps reveal other possibilities that might have helped avoid the need for an ethics committee. Ideally, the goals of care are established early in the treatment process, before a child nears the end of life, so that the family will not feel pressured to make a decision, and all interested parties would have an active role in the process (Doka, 2005; Jacobs, 2005). Reflection and consensus building among patients, families, and the medical team can help avoid or resolve conflict and some of the regrets that can make grief even more difficult to bear (Doka, 2005).

In Lauren's case, further interdisciplinary teamwork in the form of a family conference with both the oncology and hospice teams might have been beneficial. Though there is incomplete knowledge about collaboration between Lauren's parents and doctor, Lauren's parents expressed frustration to the social worker about the doctor's decision to provide cure-oriented treatment their daughter. Though Lauren was empowered by her social worker, other medical providers, and family to take an active role in her medical decision-making, collaborative efforts to develop a treatment plan where each party had a voice might have eased some of the conflict, or at least provided an opportunity for each member's perspective to be heard. Ensuring that Lauren understood that her parents held the authority to make final decisions may have also been helpful.

A related concern is the possibility that treatment team members' own emotions about a situation may impact interactions with a patient or family. Even though she was hoping for a cure, had anyone spoken to Lauren about what else she might hope for if a cure was not possible? Could the team have reframed the discussion so that it was clear they were not "giving up" on her as a person, emphasizing that they would do all they could to keep her comfortable and meet her physical, psychosocial, and spiritual needs? Did provider discomfort at knowing Lauren would die impede these conversations? Counseling interventions along with honest communication about her fears, the meaning of her life, her relationships, and her thoughts about an afterlife might have provided some solace for Lauren regarding her illness and prognosis. Additional social work interventions might have included coversations about advance directives, providing appropriate resources, planning for necessary changes related to level of care, offering information and education as the illness progressed, and ongoing contact to offer counseling and support, all undertaken with self-awareness and compassion by providers.

Continuing education, training, and supervision

Death education within social work programs is commonly only offered through elective courses and may be omitted from core courses (Walsh-Burke & Csikai, 2005) leaving social workers entering the field feeling unprepared for work in this area (Sanders, 2004). Therefore, in addition to ensuring this topic is addressed within social work education, there is also a need for continuing education to ensure competent care by those already in the field. Supervision may also help social workers become more compassionate and effective, as well as provide support necessary to continue working in an emotionally demanding field.

Strengths and limitations

One strength of using vignettes to depict ethical dilemmas encountered by practicing social workers is that the “real life” context helps elucidate practice behaviors for discussion and critique by students. The vignettes help illustrate many of the ethical tensions identified in the literature. Examining concerns of conscience as depicted by social workers in pediatric end-of-life care draws attention to the necessity of social workers understanding and adhering to the ethical standards in bioethics and those put forth by the NASW.

There are some noteworthy limitations to the selection of vignettes. One limitation is that the authors relied on student interview descriptions and were unable to obtain additional information about the vignettes or reactions from the social workers themselves. It is recognized that some of the questions raised in this article could be addressed if additional information were known. Additionally, the vignettes do not contain the full range of information known to the healthcare providers involved and may have been distorted in the process of being condensed for a course assignment. The vignettes, written by social work students as part of an assignment, were dependent upon students’ recall and/or notes, as the interviews with practicing social workers were not audio recorded. These vignettes may not reflect the kind, or range, of experiences typically faced by social workers in pediatric end-of-life care settings and should not be taken necessarily to be representative of practice in this area. Despite the limitations, these vignettes depict ethical tensions that could be valuable to explore with students and practicing social workers.

Recommendations for practice and education

Though not much is known about the experiences of social workers in pediatric end-of-life settings, research with other providers (Solomon et al., 2005) suggests that social workers may frequently encounter a variety of ethical issues when working with patients near the end of life. These vignettes allow for an initial exploration into the roles of social workers in pediatric end-of- life care and the resolution of ethical dilemmas. The use of the NASW Standards for Palliative & End of Life Care (NASW, 2004) provides further context for considering the vignettes and understanding the social workers' actions. Additionally, a number of areas were identified throughout the discussion that can serve as recommendations for competent practice in the midst of challenging ethical situations in pediatric end-of-life care. For example, while developmental assessments across the life span are an important aspect of practice, when working with children these assessments should be at the fore- front of care. Additionally, while parents and providers may feel a natural response to protect children from the seriousness of their illness, children of all ages have demonstrated a greater understanding of both their diagnosis and prognosis than what might be assumed, calling for more direct yet sensitive communication with children about their illness (Patenaude & Kupst, 2005). A child's views and preferences for care should be documented and given consideration in decision-making as well, including assent for treatment for those with decision-making capacity (Baker et al., 2008).

Interdisciplinary team meetings, or family care conferences, can help both pediatric patients and family members remain involved with decisions related to care (Baker et al., 2008). Conversations surrounding patient and family values and priorities must be approached prior to critical decision points and ethics committees should be consulted as partners across care rather than only after conflicts arise (Baker et al., 2008). Equally important is the attention focused on supporting the professional staff caring for terminally ill patients. Specialized palliative care education and structured outlets for debriefing after a patient's death have shown to help providers find meaning surrounding a loss, increasing the management of personal grief surrounding caring for dying children (Rushton et al., 2006).

One benefit of this project is that it provides a framework for educators who are interested in either incorporating a similar assignment to address ethics in their courses or in facilitating classroom conversation about ethical issues at the end of life. Given that many social workers may not have the knowledge necessary to feel competent in their roles with clients facing death or bereavement (Black, 2007; Kramer, Hovland-Scafe, & Pacourek, 2003; Sanders, 2004), and the emotional toll of working with dying children (Rourke, 2007), cases of this nature need further study. Vignettes such as these could be used in the classroom to help students grapple with the ethical conflicts that may arise in this setting, as well as to reflect on their own attitudes toward death and readiness to work in end-of-life care settings, especially those involving children. The use of realistic cases in the classroom may help students who lack experience in their own lives related to the topic of study and can encourage students to use higher level critical thinking around these issues (Nilson, 2010). One suggestion for extending the usefulness of ethical case discussion by professionals with students is to have students ask about whether the social worker would have done anything differently now that they have been able to reflect on the situation. Despite their limitations, the vignettes presented here offer insight into ethical challenges in working with terminally ill children that can benefit students and practitioners alike in their quest to improve the quality of care provided to children and their families in this setting.

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