Pediatric Palliative Care and Pediatric Medical Ethics: Opportunities and Challenges

abstract

The fields of pediatric palliative care (PPC) and pediatric medical ethics (PME) overlap substantially, owing to a variety of historical, cultural, and social factors. This entwined relationship provides opportunities for leveraging the strong communication skills of both sets of providers, as well as the potential for resource sharing and research collaboration. At the same time, the personal and professional relationships between PPC and PME present challenges, including potential conflict with colleagues, perceived or actual bias toward a palliative care perspective in resolving ethical problems, potential delay or underuse of PME services, and a potential undervaluing of the medical expertise required for PPC consultation. We recommend that these challenges be managed by: (1) clearly defining and communicating clinical roles of PPC and PME staff, (2) developing questions that may prompt PPC and PME teams to request consultation from the other service, (3) developing explicit recusal criteria for PPC providers who also provide PME consultation, (4) ensuring that PPC and PME services remain organizationally distinct, and (5) developing well-defined and broad scopes of practice. Overall, the rich relationship between PPC and PME offers substantial opportunities to better serve patients and families facing difficult decisions. Pediatrics 2014;133:S1–S7
REASONS FOR THE ASSOCIATION

The origins and causes of the association between PPC and ethics can be traced to historical and cultural factors, as well as a combination of self and social selection.

Historical

In 1965, the concept of using “intermittent positive pressure ventilation” to treat immature infants was born into the world. Although physicians had long provided care to infants who were born well before their due date, the introduction of intubation and mechanical ventilation led to the creation not only of neonatal intensive care units during the ensuing decade, but also to a host of pressing ethical dilemmas. Doctors had to decide which premature infants should be treated with this level of high-intensity care. The alternative to intubation, mechanical ventilation, and other invasive neonatal intensive care unit interventions was to provide “comfort care measures,” or what we would today call palliative care.

During the 1970s and early 1980s, the practice of issuing “do not attempt resuscitation” orders both came into existence and became a focal point for ethical debates about the involvement of parents in the process of making decisions about the medical care that their children receive. Here again, the dilemmas about the appropriate ways to care for dying children and children who have serious illnesses were the focus of both medical ethicists and of specialists in palliative care.

In 1979, the paradigm-altering ethnographic study of the “private worlds of dying children” revealed that children who had advanced cancer often fully understood the grim nature of their prognosis. Even so, the children seldom talked about their thoughts, beliefs, or dreams about dying, death, or an afterlife, maintaining this lonely isolation by a sad dance of “mutual pretense.” Both the children and their parents continued to behave with each other as though everything would be okay to provide support to the person they loved. The ethical concern of truth telling was henceforth apiece with PPC.

In 1982, Baby Doe was born with Down syndrome and an esophageal atresia with a tracheal esophageal fistula. After a decision to not operate to correct the atresia was made by his parents and physicians, the infant was treated with sedating and pain relieving medications until he died 6 days later. The subsequent outcry and passage of federal regulations underscored again the contentious dilemma of who to treat and how. More pointedly, the Baby Doe controversy brought to the fore concerns about biases against disabled individuals, as well as concerns when family interests seem to outweigh the best interests of the child, with both sets of concerns potentially leading to fundamental injustices.
These examples can be multiplied, illustrating how historically some of the most trenchant issues in pediatric medical ethics have arisen in the context of patients who have grave illness potentially confronting the end of life, with difficult decisions to make about how to best care for these individuals.

**Cultural**

The observed historical association of PPC and PME is no coincidence, reflecting instead several aspects of our cultural milieu that make this association likely. Death is an oddly marginalized topic in American culture, being on the one hand the centerpiece of violent or frightening mainstream entertainment, yet on the other hand being an issue so painful and difficult to contemplate privately or discuss publicly that doing so in a sustained, thoughtful, considered manner is felt by many to be taboo.

As a result, even though the death rate is ultimately 100%, we struggle as a society to envision the ideal care of dying individuals, to engage each other in formulating plans to assure such care, and to enact these care plans. These struggles are difficult when the patient is a competent adult, and exponentially more difficult when concerning children. PPC engages in this struggle, patient by patient. Such efforts require not only grappling with death, but also
with other difficult and marginalized issues that are central to PME, such as views regarding the value of life, the degree to which impairments do or do not diminish this value, the practical and spiritual implications of pediatric suffering, and the pursuit of a path of care that is in the child’s best interest while respecting the child’s emerging capacity to make reasonable decisions that may be contrary to the decisions of the parents.

Self and Social Selection
People who engage in PPC and PME also tend to exhibit similar personality characteristics: good collaborative communication skills, a manner of interpersonal interactions perceived by others as especially respectful and kind, an often broadly ecumenical personal world view, and an openness to both joy and sadness. This is not to say that PPC and PME practitioners have a corner on the practice of PPC and PME is a sensible use of a valuable and sometimes limited resource.

Cross Fertilization
The fields of PPC and PME can provide cross-fertilization regarding skills and intellectual agendas. The specific collaborative communication challenges confronted by practitioners in either PPC clinical consultation or PME ethics consultation can promote the further growth and development of these practice skills in ways that can benefit either realm of practice. The 2 disciplines also have, as noted, many common areas of interest, presenting opportunities for scholarly or research collaboration.

Potential Conflict With Colleagues
PPC sometimes involves conflict among health care colleagues, and PME consultation sometimes is sought to address and resolve these conflicts. To the degree that members of the PPC team are also members of the PME consultation service, the handling of the case by the PME consultation service may appear to be influenced by a conflict of collegial interests. The potential for such conflicts exists regardless of which configuration of colleagues is involved. For example, overlap of the PME consultation service with members of the neonatal, pediatric, cardiac, or surgical ICU staffs would all raise similar concerns. Although these concerns motivate some to call for PME consultation services to be staffed by individuals outside of the hospital or organization, such staffing models raise other practical concerns, while still not necessarily dissolving all potentially influential interpersonal relationships.

Administrative Efficiency
Some organizations combine palliative care and medical ethics programs, housing them underneath 1 administrative umbrella. This arrangement, which seems sensible given the overlap of PPC and PME outlined here, permits the colocation of like-minded colleagues and efficient use of support staff and joint program resources.

CHALLENGES
The overlap of PPC and PME also presents certain challenges that need to be recognized and managed.

Potential Conflict of Commitments
At a deeper level, PPC represents a certain stance regarding the goals of medical care.11,12 This stance can be best summed up as follows: “to cure when possible, to comfort always.” This philosophy of care is often accompanied by a deep sense of purpose and personal mission, which can be good or bad. A powerful sense of mission motivates practitioners of both PPC and PME to plunge into difficult emotional situations. If one’s commitment to this sense of personal mission is very strong, however, then the ability to take on the perspectives of others (which can be critical for exploring and understanding the ethical dimensions of difficult clinical situations) may be compromised. Again, this challenge is not unique to those who practice PPC. Neonatologists and oncologists, intensivists and cardiologists, surgeons and
Potential Delay or Underuse of PME

Although PME clinical consultations sometimes identify unmet PPC needs, and thereby result in a PPC consultation, the opposite does not occur as frequently. PPC consultation rarely results in a subsequent PME consult. While such a chain of events does occur from time to time, PPC staff, given their collaborative communication skills (and for some, their formal training in PME or involvement in PME consultations), may be able to manage most of the ethically challenging cases (but not all of them) and thus run a risk of not drawing on the resources and potential benefits of PME consultation in a timely manner. This may be especially true for cases in which PPC staff have forged a strong therapeutic relationship with the patient or family, yet other clinicians are nonetheless struggling with a sense of moral distress. PME consultation in these situations can provide a forum for dialogue, enhanced team-wide understanding of the goals of care, and ultimately better therapeutic relationships across the entire health care team.

Potential Undervaluation of PPC Medical Expertise

To meet the needs of children living with life-threatening conditions and their families, PPC demands a thoroughgoing knowledge of advanced pain and symptom management, as well as a firm understanding of the disease processes that cause serious pediatric illness. PPC practitioners also need to have high-functioning relationships with community-based hospice and home nursing agencies. Equating PPC only with communication and decision-support (which is to say, with the components of PPC that most overlap with PME) is to misunderstand the scope of medical expertise that PPC requires.

Potential Limitation of the Scope of Medical Ethics

Conversely, too much emphasis on the ethical issues that arise in the care of children who have serious life-threatening illness limits the scope of all the topics that PME should address. Many medical ethics issues are far afield from end-of-life dilemmas, ranging from the ethics of expanding newborn screening programs and other innovations emerging from genomic-based medical practice, to the quotidian challenges of access to high-quality care or the detrimental effects on long-term wellbeing of exposure of children to poverty or violence. Ethicists worry about the regulation of research, about enhancement therapies, and about the policy issues and looming challenges of intergenerational distributive justice. Furthermore, PME has not only an important role in performing clinical consultations, but also a vital role in the formulation or review of a wide variety of hospital policies that extend beyond the domain of PPC, as well as the provision of ethics education to members of the health care staff across the range of PME topics.

RECOMMENDATIONS

With these thoughts regarding opportunities and challenges in mind, we offer the following set of recommendations about managing the relationship between PPC and PME.

Define Clear Roles and Promote Role Identification

Health care personnel involved in both PPC or PME, like all other health care personnel, need to be clear in their own minds regarding the clinical role that they are entrusted to fulfill in the care of patients and families, and be explicit when communicating the nature and expectations of this role to patients and parents. If, in the passage of time and turn of events, a health care professional moves from one role to another in the care of a patient, this role transition also has to be recognized inwardly, and communicated clearly to patients, family members, and others.

Identify Clear Consultation Trigger Questions

Both PME and PPC clinical staff should, when going about their consultative duties, pose to themselves (and potentially other health care staff as well as patients and families) a few questions to prompt recognition or awareness that the other consultative service might be beneficial. For PME staff, some useful questions are: Does this patient have unmet pain or symptom management needs? If the patient has serious illness, are the goals of care clear? Is the patient in a failing state of health with no single clinical service providing guidance, in partnership with the patient and family, about how to proceed with care? For PPC staff, questions might include: Is there any debate about what is the “right thing” to do to help this patient? Is this debate at the level of dissension or discord? Are the patient or family feeling that they are not being heard? Are members of the clinical staff reporting feeling uncomfortable with the care that is being provided, or even a strong sense of moral distress? If now is not the “right time” to request a PME consultation, what events or discussions would indicate that the right time has indeed
teams and PME consultative services should have different names for these distinct organizational roles, along with separate budget lines and reporting structures. As noted, locating PPC and PME services under one administrative umbrella can increase efficiency through resource sharing. At the same time, clear separation needs to be maintained between the two, as they serve different roles within the organization, and if the distinctions are blurred organizationally they are more likely to be blurred at the bedside. Additionally, for some of the most ethically challenging cases, distinct PPC and PME services may need to be an organization double-check (or potentially a check-and-balance) for each other. Indeed, for such cases, PPC and PME staff can potentially role model how to address differences of opinion among health care staff regarding the best course of action, engaging in discussion that is respectful and vigorous, listening and challenging, sensitive and searching.

**Build and Maintain a Broad Scope of Work**

At the national level, the fields of both PPC and PME are promulgating practice guidance and standards, such as have been articulated by the American Academy of Pediatrics regarding PPC and PME consultation and hospital ethics committee work, and as are set forth in an increasing number of textbooks and professional society guidelines. At the local level, within hospitals and health care systems, PPC and PME programs should identify their own practice standards, including their scope of practice, and monitor whether their performance drifts over time to unduly focus on one area of their intended scope of practice while neglecting others.

**CONCLUSIONS**

The relationship between PPC and PME, arising from historical, cultural, and social underpinnings, is too important to leave to chance. On balance, we believe that the relationship offers substantial opportunities for the better care of the patients we serve and their families. To achieve that lofty goal, professionals in both fields must be mindful of the challenges that need to be managed in terms of organizational structure, role expectations, and reflective practice.

**REFERENCES**

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/content/133/Supplement_1/S1.full.html