

Pediatric Palliative Care and Pediatric Medical Ethics: Opportunities and Challenges

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KEY WORDS

pediatrics, palliative care, medical ethics, hospital care

ABBREVIATIONS

PME—pediatric medical ethics

PPC—pediatric palliative care

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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

Prologue

A 14-year-old boy, who we will call John, lies in bed. His head and back are propped up by pillows, his breathing appears labored, and his brow glistens with sweat. Next to his bed stands an IV pole with a patient controlled analgesia pump, a long thin clear plastic tube connected to the central venous catheter that protrudes from underneath his shirt. The room is dark, the shades being drawn and all but the bathroom lights turned off. Outside, in the hallway, with the door to his room closed, his parents are conversing in an animated manner with the attending physician. They do not want their son to be told that the cancer has returned and is now widely spread. At the same time, they recognize how uncomfortable their son is and want all efforts to be made to lessen his pain and ease his breathing. After a fairly lengthy discussion, the parents and the attending physician agree to requesting both a palliative care consultation, to help with pain and symptom management as well as further clarification of goals and limits of care, and an ethics consultation, to help think through the pros and cons of telling John the full truth or something less than the full truth.

For the past several decades, in the realm of pediatric hospital practice, the fields of palliative care and medical ethics have to a large degree overlapped and entwined. Indeed, this special supplement to *Pediatrics*, 1 of a series of supplements devoted to pediatric ethics, testifies to the particular relevance of pediatric palliative care (PPC) to pediatric medical ethics (PME), and vice versa. In this issue, the reader will find illuminating discussions of the ethical “hot topics” of autonomy, truth telling, futility, the role of values in decision-making, the extent of professional duties, and the line between the easing of suffering and euthanasia (all fitted out with compelling apt examples from PPC).

Even if the relationship between PPC and ethics is evident, we should not consider the depths of the relationship to be self-evident, nor should we be blasé about how to best manage aspects of this relationship.^{1,2} In this

essay, we will explore the reasons for the association (at times verging on an alliance) between PPC and pediatric ethics, consider the advantages and disadvantages of this tight relationship, and offer up some recommendations about how to manage and make the most of this set of connections (Fig 1).

In writing this essay, one of us is fully aware that he (albeit as a flawed example) personifies this enmeshed relationship, being both a practicing PPC physician as well as a practicing pediatric ethics consultant at a large children’s hospital. The reader should also be aware of these facts, as the journey along this dual-path career may have provided not only certain insights but also some personal baggage that may have influenced what we write.

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

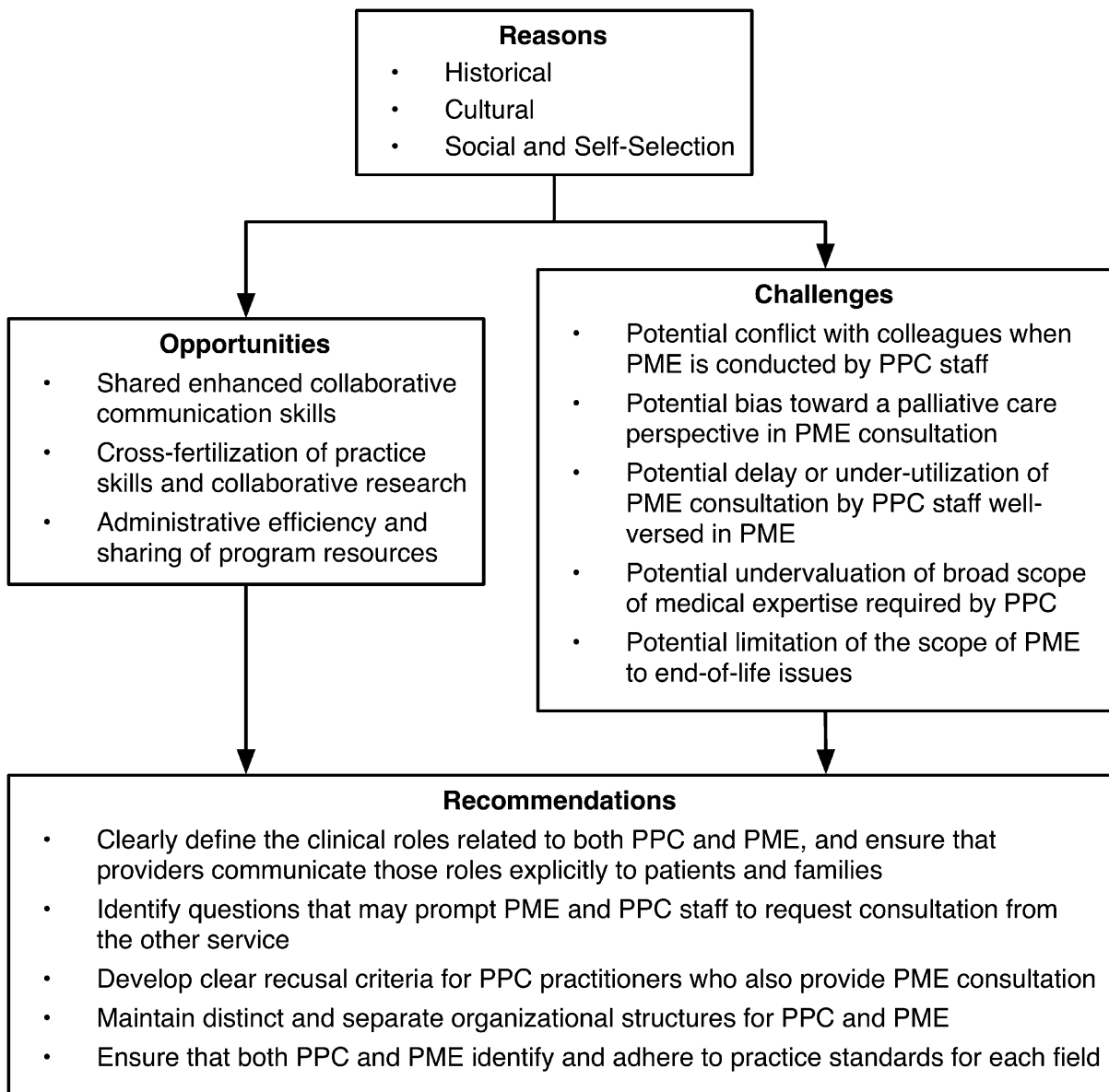
In 1965, the concept of using “intermittent positive pressure ventilation” to treat immature infants was born into the world.³ Although physicians had long provided care to infants who were born well before their due date, the introduction of intubation and mechanical ventilation led to the creation 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.⁴

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.⁵ 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.⁶ 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 a piece 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.⁷ 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.^{8,9}

**FIGURE 1**

Reasons, opportunities, challenges, and recommendations for managing the relationship between pediatric palliative care and pediatric medical ethics.

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.¹⁰ 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 market of any of these characteristics, or exhibit all of them to an exemplary degree, but these characteristics do seem to cluster in both of these sets of practitioners. This clustering may be driven by individual self-selection, based on one's sense of personal interests and strengths, or by the encouragement of others.

OPPORTUNITIES

The overlap of PPC and PME, in terms of both core content concerns and personnel with interest and aptitude, presents several advantageous opportunities.

Shared Collaborative Communication Skills

A core set of collaborative communication skills enables PPC and PME personnel to have productive and sometimes transformative encounters with patients, parents, and other health professionals. Collaborative communi-

cation can help to clarify everyone's (often differing) sense of the clinical situation, explore and support feelings of hope, fear, and frustration, examine the rationale and goals of care, and formulate consensus treatment plans. Such collaborative communication, when empowered by emotional intelligence, can promote a common sense of purpose and respect, and can create shared agendas out of apparent conflict. Having personnel who are particularly adept at collaborative communication use this skill in both 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.

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 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.

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

general pediatricians all may have deep personal and philosophical commitments that need to be managed when engaging in ethics consultation. Similarly, health care personnel who perform PME consultation are often committed to a deliberative process that may be at odds with the pace of decision-making required by a particular case, or to the attainment of consensus, which may not be possible in all cases.

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

arrived? Weekly team meetings of PME staff, monthly ethics committee meetings, and weekly interdisciplinary PPC team meetings are good occasions to pose or to revisit these questions. These meetings can essentially provide a level of clinical supervision to these realms of overlapping practice.

Develop Clear Recusal Criteria

Similarly, health care personnel involved in PME need to develop criteria that can provide prompts or guidance about when to recuse oneself from a PME ethics consultation. Individual PME providers may find themselves involved in an ethics consultation on a case in which they are intimately involved as a medical provider. Ideally, ethics consultants should bring an impartial perspective to each consult, which can be more challenging if that individual is also providing clinical care to the patient. PME consultants who also provide direct patient care need to be able to recognize the limitations to their objectivity in these circumstances and appreciate the value of calling in an outside consultant in such cases.

Maintain Organizational Distinction

Clarity of roles extends beyond the context of direct patient care: PPC

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,^{13,14} and as are set forth in an increasing number of textbooks and professional society guidelines.^{15–19} 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

1. Morrison W, Derrington SF. Stories and the longitudinal patient relationship: what can clinical ethics consultants learn from palliative care? *J Clin Ethics*. 2012;23(3):224–230
2. Carter BS, Wocial LD. Ethics and palliative care: which consultant and when? *Am J Hosp Palliat Care*. 2012;29(2):146–150
3. Delivoria-Papadopoulos M, Levison H, Swyer PR. Intermittent positive pressure respiration as a treatment in severe respiratory distress syndrome. *Arch Dis Child*. 1965;40(213):474–479
4. Lantos JD, Meadow W. *Neonatal Bioethics: The Moral Challenges of Medical Innovation*. Baltimore: Johns Hopkins University Press; 2006
5. Burns JP, Edwards J, Johnson J, Cassem NH, Truog RD. Do-not-resuscitate order after 25 years. *Crit Care Med*. 2003;31(5):1543–1550
6. Bluebond-Langner M. *The Private Worlds of Dying Children*. Princeton, NJ: Princeton University Press; 1978
7. Pless JE. The story of Baby Doe. *N Engl J Med*. 1983;309(11):664
8. Angell M. Handicapped children: Baby Doe and Uncle Sam. *N Engl J Med*. 1983;309(11):659–661
9. Lantos J. Baby Doe five years later. Implications for child health. *N Engl J Med*. 1987;317(7):444–447
10. Callahan D. The Troubled Dream of Life. In: *Search of a Peaceful Death*. New York: Touchstone; 1993
11. Cassell EJ. *The Nature of Suffering and the Goals of Medicine*. 2nd ed. New York: Oxford University Press; 2004
12. Byock I. *The Best Care Possible: A Physician's Quest to Transform Care Through the End of Life*. New York: Avery; 2012
13. American Academy of Pediatrics. Committee on Bioethics. Institutional ethics committees. *Pediatrics*. 2001;107(1):205–209
14. American Academy of Pediatrics. Section on Hospice and Palliative Medicine and Committee on Hospital Care, Feudtner C, Friebert S, and Jewell J. Pediatric palliative care and hospice care: commitments, guidelines, and recommendations. *Pediatrics*. 2013;132(5): doi:10.1542/peds.2013-2731

15. Wolfe J, Hinds PS, Sourkes BM. *Textbook of Interdisciplinary Pediatric Palliative Care*. Philadelphia: Elsevier/Saunders; 2011
16. Goldman A, Hain R, Liben S. *Oxford Textbook of Palliative Care for Children*. 2nd ed. Oxford, New York: Oxford University Press; 2012
17. Carter BS, Levetown M, Friebert SE. *Palliative Care for Infants, Children, and Adolescents: A Practical Handbook*. 2nd ed. Baltimore: Johns Hopkins University Press; 2011
18. Hester DM. *Ethics by Committee: A Textbook on Consultation, Organization, and Education for Hospital Ethics Committees*. Lanham, MD: Rowman & Littlefield Publishing; 2008
19. American Society for Bioethics and Humanities' Core Competencies Update Task Force. *Core Competencies for Healthcare Ethics Consultation: The Report of the American Society for Bioethics and Humanities*. Glenview, IL: American Society for Bioethics and Humanities; 2011

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