

Micro ethical & Relational Insights from Pediatric Palliative Care

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Abstract:

Although comprehensive palliative care is the expected standard of care at the end of life (Council on Scientific Affairs, 1996; National Quality Forum, 2006), services for the majority of children with life-limiting or terminal conditions fall significantly below those for adults.

In the India, more than 30 per 1000 live births of infants die each year before, during, or after birth as do many children with life-limiting conditions. In most countries in the developed world including the United States, the vast majority of infants, children and teenagers at end of life do not have access to multidisciplinary pediatric palliative care services in their community or at a children's hospital

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Pediatric palliative care is for children and teenagers suffering from life-threatening or life-limiting conditions in which survival into adulthood is or may be jeopardized if curative treatments fail. As a result, pediatric palliative care may last over many years.

According to the Association for Children's Palliative Care and the British Royal College of Pediatrics and Child Health (2003), pediatric palliative care is an active and total approach to care, embracing physical, emotional, social, and spiritual elements. It focuses on the enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and care through [disease], death and bereavement.

Ethics

The medical profession has long subscribed to a body of ethical statements, including the basic principles *primum non nocere* and *voluntas aegroti suprema lex*—"first do no harm" and "the will of the patient is the supreme law." These principles apply to acute care, palliative care, and end-of-life care in pediatrics. The care of children and teens with life-limiting or terminal conditions has to be measured against the worldwide acceptance of these basic principles of medical ethics:

1. **Beneficence:** "Do good" — Healthcare staff shall relieve pain and distressing symptoms and provide emotional support.
2. **No maleficence:** "Do no harm" — Painful procedures or life-prolonging treatments, which may be a burden to the child and which do not improve quality of life, shall not be performed.
3. **Dignity:** "Respect" —Health care staff shall focus on the dignity and interest of the child. Conflicting interests of staff or family members need to be addressed and resolved.
4. **Autonomy:** "Self-determination" — The autonomy of children and teens needs to be respected by including them in age-appropriate discussions about medical decision making whenever possible.
5. **Justice:** "Fairness" — All families caring for a child with a life-limiting or terminal condition need their child to receive state-of-the-art pediatric palliative care, regardless of health insurance status, financial abilities, religion, socioeconomic status, or immigration status.

In collaboration with the Institute for Professionalism and Ethical Practice (IPEP) at Children's Hospital Boston, they have developed an innovative workshop for helping clinicians engage in challenging end-of-life conversations in the pediatric intensive care unit. The workshop is now part of a large portfolio of programs focused on difficult conversations in a wide range of adult and pediatric health care settings.¹⁻³

The work of the initial IPEP programs focused exclusively on the education of clinicians who work with children with life-threatening conditions and their families—a particularly vulnerable and historically poorly served population. In light of this, perhaps the most intriguing aspect in the evolution of their work has been the number of requests they have received to design learning initiatives to address challenges in mainstream medicine, such as improving patient safety and quality,

reducing medical errors, and addressing the fragmentation of care and communication experienced by patients and families coping with complex and chronic health conditions. Many of these challenges fall into the category of “wicked problems”⁴, a term used by organizational theorists to describe problems that are especially difficult to solve because they develop in particular organizational contexts, are constantly evolving, and are held in place by the thoughts and actions of many individuals with disparate perspectives. Applying what they have learned in pediatric palliative care to mainstream medicine, they offer this working hypothesis: To effectively tackle wicked problems in contemporary health care, we will need to take a closer look at the relational and micro ethical aspects of everyday practice and cultivate robust organizational learning innovations that bring these challenges to light and provide collaborative frameworks for crafting solutions.

Choosing the career of caring for critically ill children and their families can bring extraordinary rewards as well as real burdens into the lives of health care professionals. Clinicians describe experiences that have enriched their lives forever; they also share troubling accounts of the moral distress^{5,6} that ensues when, for a variety of reasons, their caring bonds with patients and families is endangered or ruptured.

In the world of clinical ethics, there is an important body of theoretical knowledge that informs professional behavior as clinicians strive to discern and respond to the complex dilemmas that emerge in practice. Thinking through and applying such important ethical principles as respect for autonomy, beneficence, no maleficence, and justice are important competencies. Practitioners and health care organizations alike need methods for holding themselves accountable in the carrying out of professional duties and fiduciary obligations. In busy health care settings, however, more expedient micro ethics, shaped by institutional needs also can predominate: the anesthesiologist whose workload requires her to rush through a 7-minute meeting to obtain patient or surrogate consent prior to a life-threatening operation.

Though it may not seem evident at first glance, clinicians live within the same moral universe as patients and family members. When faced with difficult decisions they, too, are moral bricoleurs of a sort, cobbling together knowledge and insight from a variety of sources in order to find a way forward. In the same way that family members measure their own moral worth as caregivers, many clinicians go home at the end of a tough day, look at themselves in the mirror, and hope to meet in their reflection the best doctor, nurse, or social worker they could be on that particular day. Sadly, such elemental matters of personal and professional integrity are rarely examined explicitly in medical settings. These everyday ethics of clinicians typically remain underground unless health care leaders make a conscious effort, in the interest of professional development and ongoing learning, to coax them into the light of day.

Who gets heard? Another key microethical challenge in health care settings is the question of whose voices get heard. Bereaved parents involved in our pediatric palliative care initiative frequently describe the disabling effects of having felt, at key junctures in their health care travels, that their hard-won, intimate knowledge about their child was insufficiently valued or simply ignored by health care professionals. Examples include a parent's intuitive assessment of what a particular grimace tells them about their child's pain, their knowledge of their child's spiritual needs and preferences, or their suggestions as to the best way of communicating with their child. In these instances, the knowledge that most needs to be brought to the surface cannot, seemingly, be recognized. This is a sad irony, since the bringing together of parental expertise and medical expertise is, generally speaking, the sine qua non of optimal care for pediatric patients.

We hear parallel accounts from clinicians about their important knowledge that never finds the light of day: a bedside nurse who is afraid to say anything in a team meeting when a family to whom she is assigned is being talked about in a disparaging way; a young resident who consistently feels her attending physician communicates with families in a controlling and insensitive manner,

but cannot say anything for fear of jeopardizing her own professional advancement; a veteran social worker who finds it disheartening when, after attending a lunchtime workshop on improving teamwork, he returns to the ward to overhear co-workers heatedly complaining about problematic dynamics with colleagues that will never be discussed openly in an interdisciplinary context.

These troubling micro ethical issues are drawn from our work in the world of pediatric palliative care. They describe problematic dynamics that are unique to the particular settings in which they happen, yet they are, at the same time, recognizable in most health care organizations. They qualify as wicked problems because they are persistent, surprisingly difficult to solve, and held in place by actors with differing perspectives.

Conclusion:

If we want to address the moral and ethical components of everyday health care, we will need to expand our vision beyond a narrowly constructed medical lens and adopt a wider and more lucid perspective, one that honors the mind but also encompasses the heart, the spirit, and the relational world in which we all live. In order to see the right things and not lose our focus, we will need to learn differently together than we have. The first step in unraveling many of our wicked “macro” problems will be to discern the “micro” ethics that will help to solve them—things like treating people respectfully, telling the truth, listening to oft-silenced voices, and valuing the knowledge of patients, family members, and health care workers .

We will need to craft educational activities that are cognitively complex, emotionally challenging, and respectful of learners—spaces for learning where, among other things, we risk talking about health care realities we're not supposed to talk about.

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