

Pediatric Palliative Care in a Pandemic: Role Obligations, Moral Distress, and the Care You Can Give

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Many ethical issues arise concerning the care of critically ill and dying patients during the coronavirus disease 2019 (COVID-19) pandemic. In this issue's Ethics Rounds, we present 2 cases that highlight 2 different sorts of ethical issues. One is focused on the decisions that have to be made when the surge of patients with respiratory failure overwhelm ICUs. The other is focused on the psychological issues that arise for parents who are caring for a dying child when infection-control policies limit the number of visitors. Both of these situations raise challenges for caregivers who are trying to be honest, to deal with their own moral distress, and to provide compassionate palliative care.

CASE 1

David is a 14-year-old boy with severe cerebral palsy. He is dependent on his parents for all activities of daily living. Functionally, he is unable to hold his head up or mobilize; therefore, he requires a hoist for all transfers, for example, from bed to chair. He has epilepsy and increased tone, and he is unable to communicate and has issues with his sight and hearing. Recently, he has worsening respiratory failure and is reliant on noninvasive ventilation at night and has needed oxygen for intermittent hypoxic episodes during the day. He is fed by a gastrostomy tube, and he has an indwelling urinary catheter. This year, he has had multiple presentations to the hospital for aspiration pneumonia and respiratory failure and would usually require a stay in the PICU for high-pressure, noninvasive ventilation and one-on-one nursing. Each discharge, he is taking longer to recover. However, his mother reports he has reasonable quality of life; he loves movies and

music and laughs when his head and cheek are stroked.

He was referred to the pediatric palliative care (PPC) team because of his increasing hospitalizations and how vulnerable he is to rapid deterioration. The family has discussed advance care planning with his PPC team, and all agree that if he has a condition that is reversible, such as a respiratory infection, then it is worth treating. But he should not have cardiopulmonary resuscitation if his heart stops or if he has a respiratory arrest; instead, he should have medications to keep him comfortable and pain free.

David's mother is becoming extremely concerned about the global COVID-19 pandemic. Her concern is not whether David will contract the virus itself but that if he develops any respiratory infection during the pandemic, he will not get the usual supportive treatment he would require (ie, PICU stay and noninvasive ventilation).

David's mother has been persistently contacting the PPC team, asking for reassurance that her son will not be

abstract

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prejudiced against. The team is unable to guarantee that he would receive his usual treatment in view of the potential of PICU becoming overwhelmed with adult patients with COVID-19. The PPC team members express their concern with each other that his mother is correct and wonder about preparing his mother to start planning how to keep him at home should he become unwell. They do so, knowing that he will likely die before the end of winter because of the scarcity of resources.

CASE 2

Felicity is a 14-year-old girl from a small regional town with end-stage Ewing sarcoma. She recently presented to her tertiary hospital with acute-onset respiratory distress, and a scan revealed new metastases in her lungs. There are no further curative treatment options available to her. She has started some oral morphine for breathlessness and some low-flow oxygen.

Her parents are obviously devastated, and a referral was made to the PPC team for support and advance care planning. When discussing where she wants to be for end of life, both the parents and Felicity feel safe in the hospital. They feel that their regional town is too far away for medical support, and they have lived here on and off for the last 2 years of treatment and follow-up, making them feel at home and comfortable with staff they know care about them. Her parents are feeling extremely shocked and overwhelmed by the recent poor prognosis and the possibility that she is dying. They also express their need to be her “parents,” rather than her “carers.” They have all agreed to stay in the hospital.

Felicity is 1 of 4 girls, and, along with her parents, she has an extremely supportive and large extended family. Felicity is loved by many, including her friends at school, her many peers

in her local community, and the hospital nurses and doctors.

She remains in the hospital for a few weeks, and there is a noticeable deterioration in that time. She is becoming more fatigued, she is sleeping most of the day, and her mobility is decreasing. She is now unable to mobilize because of fatigue and breathlessness. She has many visitors and saves her energy for small bursts of time when they are in the room. She enjoys leaving her room and being walked around in the chair to get out and about.

When the COVID-19 pandemic occurs, the oncology ward is nervous about what this means for their vulnerable population. It takes a few weeks until the reality of the pandemic transpires, and visitors are restricted. Initially, exceptions are made for Felicity: she could still go out and about to see friends, whereas other patients were not allowed. But after a week of this, the hospital’s policy was tightened: 1 parent only at the bedside and no siblings, and for dying children, 2 parents only at the bedside.

The PPC team did everything they could to advocate for Felicity. She had started deteriorating rapidly and would likely only survive days; however, the policy had to stand to protect the other patients. It was heartbreaking not being able to fulfill Felicity and her family’s wishes for togetherness at the end of her life.

In the context of this pandemic, the family decided to ask for discharge and left the hospital that day. Felicity was transferred semiconscious to a family home with the support of

community palliative care nurses and the PPC team. She died a few days later, comfortable and surrounded by her family.*

DISCUSSION

Moral Distress

Clinicians who are unable to provide care that they regard as clinically indicated often experience moral distress. This reaction, rooted in their own sense of professionalism, is likely to be exacerbated by the distress, alarm, fear, and recriminations communicated by families after learning that their child will be unable to access services that they depend on (eg, David’s case). Parents who have relationships of trust with clinical teams are also likely to experience moral distress as they realize the impact of withdrawal of access on their own ability to meet their child’s needs (eg, Felicity’s case).

Moral distress refers to the experience of being unable to take the action that one believes to be morally right or required.¹ It has been reported across a range of medical and nursing specialties, including pediatrics,² intensive care,³⁻⁵ and palliative care.^{6,7} Common precipitators of moral distress include the inability to provide care because of resource constraints, involvement in care that one deems to be against a patient’s interests, and disputes about care planning with families and within teams.

Working within the COVID-19 pandemic, in which all of the above can occur, many clinicians are

* In this case, the child was able to leave the hospital to be with her family, but, sadly, in cases of COVID-19, this will not occur. There are stories of adults dying alone as their family remain in isolation, and this goes against all we try to achieve with palliative care and the reason most of us do our jobs. Maintaining relationships and communication at the end of life is of upmost importance to us, and it is hard to reconcile these 2 opposing worlds and provide the best care possible.

experiencing moral distress. For some who are in the hardest hit areas, moral distress is a daily concern. For others who are working in areas that have not yet been overwhelmed, the anticipation of distress is palpable. Reports from hardest hit areas^{8,9} permeate the thoughts of our Australian-based PPC team as we face the prospect of being unable to meet dying patients' and their families' wishes and needs. We anticipate that a lack of resources may soon contribute to earlier-than-expected deaths.

In contrast with moral dilemmas (in which there is no apparent right action), moral distress is produced when an agent recognizes an act as morally required but is constrained from acting. Such is the situation for the PPC teams in the above cases. They know what ought to be done. They just cannot do it because of the circumstances. A moral judgment underlies the deeply uncomfortable, often emotional experience of moral distress, but the details of that judgment may be partially submerged in the affective dimensions of distress. The confusion that accompanies moral distress amplifies its negative effects. Pulling those judgments to the surface enables their conscious consideration. That process may partially alleviate distress and point to a way forward.

One reason that it is important to acknowledge and address moral distress is that such distress can produce a sense of helplessness and personal futility, feelings that disable and can promote emotional and physical withdrawal from distressing situations. Because moral distress is a response to the inability to act as one perceives one should, it may cause a sense of ineffectiveness in one's professional role. When we feel ineffective, we are less inclined to act at all. These feelings have contributed to professional burnout and an intent to leave current roles.²

Identifying the feelings of moral distress and the source of those feeling can help clinicians move through the paralysis and focus on practical and action-oriented solutions. When standard clinical options are unavailable, it is more important than ever to look for ways to provide care and support to families. Although standard options for meeting the needs of patients and families are unavailable in both David's and Felicity's cases, meaningful options remain. Careful (in both senses of the word) assessment of one's professional role obligations can alleviate guilt, restore a sense of agency, and encourage continued outreach to families in need.¹⁰

PPC teams are accustomed to providing care that addresses need, improves well-being, and relieves suffering without seeking to resolve the underlying cause. Usually, the underlying cause is an incurable disease. In these cases, the underlying cause is an overwhelmed health care system. Doctors who are providing care in these situations need to understand that it is not their fault that they are working in a nonideal situation in which established best practices are not available and the available options seem inadequate. In these circumstances it can feel as if one is failing to meet one's role obligations because role obligations are connected to provision of quality care. The contrast between the service one would seek to provide (and which would be recognized by peers as optimal or even adequate) and the service that one can provide can feel debilitatingly unacceptable. Why bother at all if all we can do is stand by and watch as children die without the usual and expected support?

Usually, the tough task of providing care to children at end of life is weathered through sitting within distress and providing comfort by being present. Additionally, reward is

garnered by making an intolerable and painful situation a little more tolerable by providing the best care that can be offered. The stakes are high, humans only die once, and the pain of a child dying is intense. Clinicians want to do anything humanly possible to alleviate that pain and to get it right. When we cannot and when the care we provide is less than what we know is possible and expected, we end up suffering as we helplessly bear witness to care that feels unacceptably inadequate.

Role Obligations and the Realm of Possibility

The connection that we draw between professional role obligations and best practice standards can be misleading. Standards govern the realm of what is possible; ideals govern the realm of what should be possible. In Kantian-inspired reasoning about duties, the principle "ought implies can" functions to situate our obligations within the realm of possibility.¹¹ We cannot have an obligation to save a life that cannot be saved: we can only be obliged to do what we can. Of course, it is important to question assumptions about what is possible and to strive for better things. But rather than encouraging complacency, recognizing that we can only be obliged to do what we are able to can be empowering. It can help us focus on what is possible rather than what is ideal. And what is possible may be more than what first appearances suggest.

In these cases, it is not within the PPC team's gift to provide access to previously available services and conditions when crisis management policies kick in. Applying "ought implies can," the team does not fail when access is withdrawn. Although the PPC team is likely to be charged with communicating the policy and its impacts, the policy is not their act. Although they would normally be responsible for advocating for

a patient to be admitted to the PICU on the basis of their clinical judgment, that responsibility and the discretion it entails has been lifted from them. One way of dealing with moral distress is to see that as a clinician providing care in these circumstances, the situation is not one of your making. It is not your role, as a clinician, to change the policies and to transform the situation into one that is preferable to your patient. It is only your role to act well within your scope of responsibility and to be the best clinician that you can be under the circumstances.

Recognizing the limits of one's powers can relieve a burden of guilt that is unconnected with one's own choices and actions. It does not reduce the suffering, distress, and grief of patients and families that form the focus of palliative care. It also does not protect doctors from their own feelings of distress and grief. But it should absolve clinicians of feelings of guilt or self-blame for their own and their patients' and families' suffering. Although these cases can feel hopeless and the clinicians feel helpless, shifting focus from what one cannot do to what one can is potentially a key element in continuing to provide care for these children in these times.

The Expressive and Relational Elements of Care

Pandemic ICU access policies¹ may prevent children from receiving the clinical support that they would otherwise receive and could benefit from. These policies clearly place tremendous practical and emotional burdens on families and force them to accept or make unbearable decisions. Significant elements of the pediatric palliative role are simply to acknowledge suffering, to respond to it with care, and to be present for the patient and the family. The importance of these acts of presence, witness, and compassion can be

obscured by the tasks and tools of clinical activity, but evidence suggests that patients place a high priority on the relational elements of medical care.^{12,13} Wool et al¹⁴ demonstrated this within the antenatal context, in which 92% of parents, when questioned, felt satisfied with the care provided, despite knowing that their infant would not survive, because of the compassionate support offered to them to help them cope.¹⁵

Clinical experience and research suggest that families remember the compassion of the clinician over the words used when bad news is delivered with empathy, intention, and honesty.¹⁶ Children also appreciate honesty, and knowing bad news does not mean they stop planning for their future, it does not affect adherence to medication regimes, and more importantly, they do not lose hope.¹⁷⁻²⁰ Surprisingly, those who have increased hope (measured on hope scales designed by researchers) are more likely to discuss advance care plans, which some would consider as being a threat to hope.²⁰ Allowing families space to prepare for their child's death, giving them the opportunity to reflect on what is important to them and working creatively to have their wishes met, is enough to provide families emotional containment and peace. PPC teams achieve this with relationships and connection and are able to provide this despite lack of access to the hospital.^{21,22} Families report that having a team at the end of the phone whenever they reach out empowers them and allows them comfort.²³ PPC teams may need to institute mechanisms to sustain them through the challenges ahead. Attention to team dynamics,³ unit-level debriefing,²⁴ and ethics consultations may enable maintenance of purposeful connections despite shared distress.^{25,26}

Another way in which pediatric palliative doctors can serve their

patients when they cannot provide standard therapies is through advocacy. Decision-makers should understand the impact that resource prioritization will have on this vulnerable patient population and should have the opportunity to consider their decisions in light of that knowledge. PPC teams can request that policies take into account and, whenever possible, meet the needs of children with palliative requirements; for instance, if priority tools for determining access are being used, teams could request that children in need are considered for access to the PICU through those tools along with other patient groups (rather than imposing blanket withdrawals of access to all patients within a given service for a specified time period). They could also request that due weight is accorded within measures of capacity to benefit to dimensions of health gain that matter to this cohort. PPC teams must be among those policy decision-makers when determining distribution of resources for children.

Maintaining Trust in the Aftermath

The world is facing an indefinite time of uncertainty in the face of the COVID-19 pandemic. For families under palliative care, this uncertain world is their day-to-day reality: they have been self-isolating for many years because they know any respiratory illness can mean death for their child, and they do not know if their child will have a life-threatening seizure or, for those who have malignancy, when a relapse could occur. They have built necessary resilience in facing uncertain futures. These families have also been within the health system and understand the constraints of a system that already bursts at the seams. Intensivists may have brought their child back from the brink of death many times in the past, revealing the vulnerability time and time again that their child faces. But losing a health system they know and expect is a different world to

them. This new lack of access to resources that they would expect and have received in the past will create feelings of betrayal, loss of control, and, more importantly, loss and grief.

PPC teams are equipped to support families within this space; many times, they have been present when the delivery of bad news has occurred and have accompanied these families in their grief. Although this pandemic is something we have not faced before (in recent history), PPC teams' ability to provide companionship and sustain connection within the trauma and bear witness to the families' pain will be enough to maintain trust.

CONCLUSIONS

Faced with the incoming tide of the COVID-19 pandemic and the likely shortages that will result, we all need to focus on what we can do rather than on what we cannot do. Vulnerable families like Felicity's and David's will require more skilled and sensitive communication than ever in these difficult times. Clinicians will undoubtedly feel distress when unable to provide indicated therapies. We need to help each other remember that we can always offer companionship and compassionate communication. These can be empowering by helping to ameliorate loss of trust, grief, and moral distress in a world that is uncertain. It is up to the PPC teams to demonstrate that despite lack of resources, we still have care that we can give.

ABBREVIATIONS

COVID-19: coronavirus disease 2019
PPC: pediatric palliative care

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