

Physician Moral Distress and End-of-Life Physician-Parent Communication and Care

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Abstract

Objective: By exploring perspectives of pediatric specialists on end-of-life (EOL) communication and care through narrative interviews, we aim to examine the extent to which interactions about death lead to feelings of moral distress.

Methods: 17 pediatric emergency medicine and pediatric critical care physicians practicing in a 380-bed academic children's medical center in the southeast went through 2 rounds of narrative interviews. The overarching interview question in Phase I was: "How has your background influenced the way you communicate with and care for dying children and their families?" The data generated from the interviews in Phase I led to additional questions and topics for exploration in Phase II. Grounded theory informed the design of this study and analysis of the data.

Results: Although most participants felt that EOL decisions were the families' jurisdiction, the physicians described experiencing moral distress in some cases, especially when they felt they were forced to put the parents' prerogatives over the child-patients' best interests. Moral distress ensued from observing other physicians withdrawing life-sustaining care too soon, from parents prolonging care contrary to what these physicians thought were the child best interests, and issues surrounding resuscitation and organ donation.

Conclusion: Research indicates that physician burnout is more prevalent among those physicians in palliative care who feel inadequately trained in communication skills. In addition to promoting better patient care, more education and training in communication and EOL issues may prevent physician moral distress which can decrease physician burnout and ensure more efficacious humane patient care.

Keywords: Moral distress; Pediatrics; End-of-life care; End-of-life communication; Grounded theory; Qualitative methods; Physician-parent communication

Introduction

In pediatric end-of-life (EOL) care, the partnership between physicians and parents is principally centered on communication and the parents' decision-making role about the patient's likely death. Research indicates that this communication is often poor [1-3]. However, because parents are charged with EOL decision-making for their children, physicians are morally responsible to ensure that prognoses and treatment options are communicated to parents in a comprehensible way. Information-giving that is clear, truthful, and timely encourages parents to choose optimal care for their child, which often is palliative care over life-sustaining measures [4]. The literature confirms that poor EOL communication with parents of dying children can cause significant difficulty for physicians as well as families. And, these difficulties may affect their personal well-being and practice of medicine [5-8].

One type of difficulty reported by physicians who practice in EOL care is the experience of moral distress, the inability to do what one considers morally correct due to external or internal obstacles [9,10]. Research has indicated that situations which cause the most moral

distress for physicians involve the continuance of aggressive care they feel is unwarranted [11-15]. Moral distress has been described in pediatric EOL care in particular [5,15].

Poor communication may be related to moral distress in that inadequate information-giving by the physician may result in questionable EOL decisions made by parents on behalf of their children. In some cases, physicians may feel they have discussed the terminal prognosis of the child, but the parents may not have been able to hear and comprehend the discussion [1]. Parents may advocate for life-sustaining measures if they do not fully understand the situation or that alternative measures, like comfort care, are available. In order to understand the phenomenon moral distress as it relates to EOL physician-parent communication, further research is necessary. In this qualitative interview study, by exploring perspectives of pediatric specialists on EOL communication and care, we aim to examine the extent to which interactions about death lead to feelings of moral distress.

Methods

Participants and procedures

Participants included pediatric emergency medicine (PEM) and pediatric critical care physicians (PEM) practicing in a 380-bed

academic children's medical center in the southeast (Table 1). We recruited 17 of the original 21 participants via email who took part in a prior high-fidelity simulation study that examined the quality of EOL communication between participant physicians and an actor parent. Participants were offered a \$50 gift card as an incentive for participation. Individual narrative interviews, conducted in a place convenient to each participant, were audio recorded and took 30-45 minutes. This study was approved by the Institutional Review Board for Human Use at the University of Alabama at Birmingham (UAB), Protocol #E120130002. Funding for the participant incentives was provided by a grant from the UAB Center for Social Medicine. For more information about the overall study, Bateman et al. [16].

Variables	Phases I and II (N=17)
Sex	
Female	6 (35.3%)
Male	11 (64.7%)
Race/Ethnicity	
White	15 (88.2%)
Nonwhite	2 (11.8%)
Specialty	
PEM	8 (47.1%)
PCC	9 (52.9%)
Rank	
Fellows	6 (35.3%)
Attending	11 (64.7%)

Table 1: Demographics of participants.

In Phase I, the overarching interview question was: *How has your background influenced the way you care for dying children and their families?* This question was designed to explore participants' perceptions about how their experiences have influenced their children at the end-of-life and in what ways that care has been influenced. In keeping with the principles of both grounded theory and narrative interviewing, the questions served as a guide but participants were permitted to discuss additional topics that they felt were important.

Phase II was proposed as new topics emerged from the Phase I interviews that warranted further exploration. Each of the 17 participants from Phase I consented to participate in another 30-45 minute individual narrative interview. Each participant was offered an incentive of a \$50 gift card. The interview guide for Phase II was developed from topics that arose in Phase that we wanted to explore further (Table 2). Please see Appendix for complete interview guide.

Grounded theory informed the design of this study and the analysis of the data. An important principle of grounded theory is the idea that emergent conceptual themes are pursued intentionally by asking new questions in subsequent interviews. In this study, ideas that emerged during the Phase I interviews led to an additional wave of interviews, Phase II.

Coding and analysis

Narrative interviews were transcribed and coded in two phases according the guidelines of grounded theory and organized for analysis using Atlas.ti version 7.0. The coding process of grounded theory proceeds in a hierarchical fashion beginning with narrative data. Initially data was coded line-by-line. As line-by-line coding proceeded, more 'focused codes' were developed to represent recurring concepts that were beginning to emerge from the data. Throughout the coding process, codes were deleted, trimmed, renamed, and merged codes by the authors into larger categories that corresponded to themes in the data.

Findings

Although most physicians felt that EOL decisions were the families' jurisdiction, the physicians described experiencing moral distress in some cases, especially when they felt they were forced to put the parents' prerogatives over the child-patients' best interests. Moral distress ensued from observing other physicians withdrawing life-sustaining care too soon, from parents prolonging care contrary to what these physicians thought were the child best interests, and issues surrounding resuscitation and organ donation. The results are summarized in Table 2.

Withdrawing care too soon: Two physicians mentioned the difficulties they had, while they were trainees, in observing EOL decisions in children born with anomalies. When asked whether or not he experienced moral distress, one male PEM attending in the stated, "Yeah ...I saw some of my teachers basically say that Down's Syndrome is incompatible with life and we are not going to do anything about this child's Down's Syndrome's birth defects... And I never personally believed that..." The other participant, a female PCC fellow, described a case of an infant she describe as "not genetically normal," and her attending made the decision to extubate the patient when his mother was not in the unit. The baby died subsequently, and the participant stated that, "... I struggled with the perception that ...if he's genetically abnormal then we're not going to try too hard"

Prolonging care/overtreatment: Contrary to the above cases, most moral distress ensued from parents who wanted to continue life-sustaining care against what these physicians felt was in the best interests of their patients. One male PEM approached the idea of moral distress,

I don't know if there's a way to deal with it when there is no option for me as a physician. I just have to go through the motions and do what the parent wishes....But there's many times when it's not that clear and we see patients every day ...that the child is absolutely vegetative, there's no level of interaction whatsoever, and we're keeping them alive for 10-15 years...

This same participant expressed his concern that the issue of palliative care was not addressed adequately in pediatrics, "How do you make them comfortable through that versus put them through hell, more hell, you know? I don't pretend to have to answers to that, but it's a question we should be asking and no one is."

A female attending expressed moral distress about following through with parents' wishes against her better judgment,

But there have been times when children with terminal diseases have come in, whose family members have a different idea about what medical care should be administered than I do, and I do what they ask,

but I get quite upset by it. And it flavors my month. Like, it's not something that I easily shed and get rid of... I carry it with me maybe longer while I kind of slowly process it, and try to understand what their thoughts are, although really all I see is that the child is suffering.

Theme/Subtheme	Quotations
Theme: Causes of Moral Distress	See Subthemes
Subtheme: Withdrawing Care Too Soon	<p>"Yeah ...I saw some of my teachers basically say that Down's Syndrome is incompatible with life and we are not going to do anything about this child's Down's Syndrome's birth defects... And I never personally believed that..."</p> <p>"... I struggled with the perception that ...if he's genetically abnormal then we're not going to try too hard."</p>
Subtheme: Prolonging care/overtreatment	<p>"I don't know if there's a way to deal with it when there is no option for me as a physician. I just have to go through the motions and do what the parent wishes....But there's many times when it's not that clear and we see patients every day ... that the child is absolutely vegetative, there's no level of interaction whatsoever, and we're keeping them alive for 10-15 years..."</p> <p>"But there have been times when children with terminal diseases have come in, whose family members have a different idea about what medical care should be administered than I do, and I do what they ask, but I get quite upset by it. And it flavors my month. Like, it's not something that I easily shed and get rid of... I carry it with me maybe longer while I kind of slowly process it, and try to understand what their thoughts are, although really all I see is that the child is suffering."</p> <p>"They say if God wants to take them, God will take them no matter what you do. And, the problem with that is when they want you to do everything, when honestly when you do everything you're making the child suffer..."</p>
Subtheme: Resuscitation	<p>"If we resuscitate someone that...we didn't know was a no code or we spent longer than we should have or for teaching purposes we let a resident do a procedure in part of the resuscitation and they ended up coming back unexpectedly....knowing full well that the child is going to die... they consume significant resources and some of those incur significant debt..."</p> <p>"...you don't want to give up, because the mom is screaming at you, 'Please, do everything, do everything! Don't give up!' And yet, you know, at 20 minutes, at 30 minutes, at 40 minutes out from the heart stopping that the outcome is very bad... You could potentially get a kid back and put a family through the life-long change because their child is now debilitated and requires 24-hour care...And nobody knows the right answer."</p>
Subtheme: Organ Donation	<p>"I had a family that, we had just pronounced the child and...the dad said, 'I want her disconnected now.' And, I told them, why don't we just take some time? Let's wait and be patient with this. And, he just out of the blue said, 'So, what for, so you can harvest her organs?' No, no, no, no. And, yes. She was a potential candidate and we need to think about it, but it's...a difficult decision because you know that child is dead and there is nothing you can do for that child, but there is another child somewhere in the country that might benefit from the organ. But, at the same time you don't want to insult the family or go against their wishes. But, you sort of have to bring it up. And, all the literature related to organ donation says that almost unequivocally, most families, after the donation feel very fulfilled by it. In a way the literature backs up the idea that it's a good thing to try to convince them."</p> <p>"We sometimes have patients that we know have a fatal situation and everything is futile, but we may be able to delay it for a very short period of time. Should we delay it with the intention that we try to get an organ donor out of this? Try to have something good to come out of this? Or, is that, pushing the limits?"</p> <p>"I just kind of worry that one of my cases is going to be promoted for DCD, because I'm not sure how I'm going to feel about it. And you can argue either way. You can argue that it's immoral to have a patient pass away and have their organs not be available for someone else to survive. It's wrong. Or, you can argue that it's wrong to take organs from somebody who, the circumstances are a little sketchy under which they were taken."</p> <p>"It feels like you're ripping the child out of mom's arms and they can't just sit there and grieve and hold their child."</p>
Dealing with Moral Distress	<p>"You need people that don't feel comfortable pronouncing children dead, and you need people who do feel okay with it, and realize that we're not in control of when the human body dies."</p> <p>"...the ethics for me is making sure the whole team is comfortable with the decision."</p> <p>"I don't know if there's a way to deal with it when there is no option for me as a physician. I just have to go through the motions and do what the parent wishes"</p> <p>"...put some distance between me and that. I mean cause you go home and sleep on it. Things are a little bit better the next day. The situation hasn't changed but you feel a little bit better when you have a little bit more distance I think."</p> <p>"The majority of the time, this is something that no one wants to hear about, and you can't easily talk about this kind of thing. So I think I carry it with me maybe longer while I kind of slowly process it..."</p>

Table 2: Themes and representative quotations.

Likewise, a female fellow was frustrated when families used their faith to demand life-sustaining treatments, "They say if God wants to take them, God will take them no matter what you do. And, the problem with that is when they want you to do everything, when honestly when you do everything you're making the child suffer..."

Some of the physicians expressed frustration at the cost of treatments they deemed futile. One male attending stated, "And, the

child is vegetative and we have resuscitated him from death 6 or 7 times now. And that's an example of when I react that this makes no sense. Not only putting the child through that, but the cost associated with that care is phenomenal..." Another female attending stated that although she always follows parents' wishes, "I do have a lot of conversations about really the waste of resources like this is really not worth it to go down this road, this predictable road, leading a child to

long intensive care unit stay of someone who is clearly not having a high quality of life. I do feel conflicted.”

Resuscitation: The PEM physicians spoke at length about the ethics related to resuscitations and the moral distress that emerged from the associated ambiguities. Physicians described cases where it was difficult for them to stop resuscitation, even though they knew continuing was futile. These were cases where they related to the patients or the families on a personal level or where the situation was sudden and traumatic. They explained that if resuscitation was successful, the child is likely to have suffered neurological damage. And, the longer the resuscitation takes to get a heartbeat, the more severe the damage is likely to be. A male attending expressed his frustration, “If we resuscitate someone that...we didn’t know was a no code or we spent longer than we should have or for teaching purposes we let a resident do a procedure in part of the resuscitation and they ended up coming back unexpectedly...knowing full well that the child is going to die... they consume significant resources and some of those incur significant debt...”

Although the prognosis is poor, resuscitations are continued for a variety of reasons, according to the participants. They may be continued so that the patient may be an organ donor or for training purposes. However, primarily, they are continued because the staff is waiting for the parents to arrive. Because the child often arrives in the emergency department in the ambulance before the parents, physicians feel that they need to continue resuscitation until the family arrives because, “the family needs to see that you’ve done and are doing everything. Because they will never forget this moment...and need to know that you did everything that you possibly could to save their child.” Physicians felt it was important for parents to witness the resuscitation and if that is too difficult, to at least give the parents a chance to say “good-bye” before the resuscitation is ceased.

The ethical question for the physician becomes, how long do I continue resuscitating? Several PEM physicians mentioned conventions that they had determined over their time in practice in terms of number of rounds of CPR and doses of epinephrine. But difficulties ensued from parents. One male PED participant stated,

...you don’t want to give up, because the mom is screaming at you, ‘Please, do everything, do everything! Don’t give up!’ And yet, you know, at 20 minutes, at 30 minutes, at 40 minutes out from the heart stopping that the outcome is very bad...You could potentially get a kid back and put a family through the life-long change because their child is now debilitated and requires 24-hour care...And nobody knows the right answer.

This participant described that when he continues resuscitation too long and does get a heartbeat back the family celebrates, yet the staff “feels sick to our stomachs” because of the prognosis of the child.

To attempt to resolve the ambiguities related to resuscitations, the idea of drawing wisdom from the community emerged. A female PEM attending stated that, “You need people that don’t feel comfortable pronouncing children dead, and you need people who do feel okay with it, and realize that we’re not in control of when the human body dies.” A male PEM attending summed up the feelings of the PEM participants saying, “...the ethics for me is making sure the whole team is comfortable with the decision.” And, it is often through the consensus of the team that attendings decide when to cease the resuscitation.

Organ donation: Six of the participants mentioned distress over ethical issues surrounding organ donation. Three main subthemes emerged related to organ donation: communication with families about organ donation, whether or not it was ethical to keep a child alive only for the possibility of he or she becoming an organ donor, and the ambiguities related to procedure of donation after cardiac death (DCD). The difficulty of discussing organ donation with families can be seen in this extended response from a PCC male attending physician,

I had a family that, we had just pronounced the child and...the dad said, ‘I want her disconnected now.’ And, I told them, why don’t we just take some time? Let’s wait and be patient with this. And, he just out of the blue said, ‘So, what for, so you can harvest her organs?’ No, no, no, no. And, yes. She was a potential candidate and we need to think about it, but it’s...a difficult decision because you know that child is dead and there is nothing you can do for that child, but there is another child somewhere in the country who might benefit from the organ. But, at the same time you don’t want to insult the family or go against their wishes. But, you sort of have to bring it up. And, all the literature related to organ donation says that almost unequivocally, most families, after the donation feel very fulfilled by it. In a way the literature backs up the idea that it’s a good thing to try to convince them.

The participant explained the distress he felt by knowing that organ donation can be a potentially healing decision for families, yet mentioning it to families in shock can be insulting.

Participants also felt moral distress about whether it was ethical to delay death in acute cases for the sole purpose of the patient potentially being an organ donor. For example, one attending summed up the ambiguities, “We sometimes have patients that we know have a fatal situation and everything is futile, but we may be able to delay it for a very short period of time. Should we delay it with the intention that we try to get an organ donor out of this? Try to have something good to come out of this? Or, is that, pushing the limits?”

Two participants mentioned that they were genuinely troubled by (DCD). In DCD an organ donor has suffered an irreversible brain injury, but does not meet formal brain death criteria. Moral distress ensued from the ambiguity surrounding the DCD procedure: the lack of guidelines related to the length of time after cardiac death before organs are removed, whether or not the patient can still feel pain given that no anesthesia is given, and the fact that families may not have adequate time to mourn in the presence of the body before the body is whisked off to have the organs removed. The participants clearly desired more evidence-based guidelines for the DCD procedure, ethical guidance about organ donation in general, and more training in communication about organ donation. One PCC male attending stated,

I just kind of worry that one of my cases is going to be promoted for DCD, because I’m not sure how I’m going to feel about it. And you can argue either way. You can argue that it’s immoral to have a patient pass away and have their organs not be available for someone else to survive. It’s wrong. Or, you can argue that it’s wrong to take organs from somebody who, the circumstances are a little sketchy under which they were taken.

And the issue of hurriedly taking the child away from grieving parents is difficult for others, “It feels like you’re ripping the child out of mom’s arms and they can’t just sit there and grieve and hold their

child." With few evidence-based guidelines and ethical confusion these physicians felt uneasy about DCD.

Dealing with moral distress: By definition, moral distress ensues when health care providers cannot act in accordance with their moral beliefs because of either internal or external obstacles. But, if moral distress is inherent in practice and results from the inability to do what one thinks is right, how can a physician deal with the distress so that he or she does not experience emotional exhaustion? Some participants could not think of a way to deal with it, such as the male attending, "I don't know if there's a way to deal with it when there is no option for me as a physician. I just have to go through the motions and do what the parent wishes." Most agreed that moral distress was just something one has to deal with as part of being a physician who treats dying children. Some said that they divorce themselves from quality of life issues or "compartmentalize that off."

Others said that taking time away provided some benefit. A male PCC fellow claimed that he, "...put some distance between me and that. I mean cause you go home and sleep on it. Things are a little bit better the next day. The situation hasn't changed but you feel a little bit better when you have a little bit more distance I think." A few discussed seeking support from spouses and colleagues, but finding support from others may be difficult. As a female attending shared, "The majority of the time, this is something that no one wants to hear about, and you can't easily talk about this kind of thing. So I think I carry it with me maybe longer while I kind of slowly process it..." What did seem to help decrease moral distress was discussed in the above section on resuscitation - drawing wisdom from colleagues and consensus among health care team members.

Discussion

Many aspects of EOL care can generate difficulties for physicians of dying children. Their inadequate training in end-of-life discussions [17-19], the grief they experience from patients [19-22], and the moral distress they feel when parents' decisions conflict with their beliefs about what is best for a particular patient [5,11-15] all have the potential to affect the patient care process as well as physician well-being. And, there are few formal mechanisms in place to help physicians of any rank deal with personal grief or moral distress, and continuous exposure can lead to physician burnout and personal pain [5,23,24]. An Institute of Medicine [4] report, *When Children Die: Improving Palliative and End-of-Life Care for Children and their Families*, suggests that strategies must be developed to support clinicians who deal with pediatric death in order for them to continue to provide quality care.

Strategies to deal with moral distress emerged in this research. First, participants suggested that taking time away from work and seeking support from family and friends can help. It was also suggested that seeking wisdom from other physicians and coming to a consensus, as in the case of ceasing resuscitation, can ease the discomfort with having to make difficult decisions in isolation. Finally, it was suggested that the establishment of evidence-based guidelines for the practice of DCD would decrease some of the ambiguities surrounding it.

In addition to evidence-based guidelines that might reduce ambiguities associated with resuscitation and organ donation, moral distress could likely be reduced if physicians understood better how their language could potentially lead to families' refusing to limit care. Perhaps training in EOL communication could lead to a decreased occurrence of moral distress by helping physicians truly balance hope

with information-giving in ways that facilitate ensuring that parents are clear on their child's prognosis and not holding on to unrealistic hope. Finally, the simple act of having open, truthful conversations with families may alleviate the distress physicians feel when they perceive ethical issues that they cannot change (Ulrich, Hamric and Grady 2010). However, conversations around difficult issues, such as the impending death of the child-patient are rarely simple.

It cannot be determined from this study the extent to which moral distress may influence physician-parent EOL communication, but understanding the significance of moral distress will ideally lead to studies that can examine its role. Research indicates that physician burnout is more prevalent among those physicians in palliative care who feel inadequately trained in communication skills [7]. In addition to promoting better patient care, more education and training in communication and EOL issues may prevent physician moral distress which can decrease physician burnout and ensure more efficacious humane patient care.

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