

Health Care Law

Mid-Atlantic Ethics Committee Newsletter

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Newsletter, Fall 2010

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MID-ATLANTIC ETHICS COMMITTEE

NEWSLETTER

A Newsletter for Ethics Committee Members in Maryland, The District of Columbia and Virginia
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MORAL DISTRESS— MISUNDERSTOOD, MISAPPLIED

As an ethicist for a four-hospital Catholic health system in Wisconsin, I do not believe we present any uniqueness concerning the complexity of issues addressed by our ethics committees. In some instances the referrals we receive for ethics consultation are circumscribed by a general frustration or professional distress in the level of care (or lack thereof) requested by the patient or family in relationship to the patient's clinical acuity. When such frustration or distress is identified as one concern among many related to the conflict that warranted ethics consultation, it is often termed "moral distress." Given the prevalence of this term in the bioethics literature, it is my view that "moral distress," as a concept, requires a re-examination in light of its original meaning offered by Andrew Jameton in 1984.

Jameton implicitly crafted a definition of moral distress in his book *NURSING PRACTICE: THE ETHICAL ISSUES*: "...moral distress arises when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action" (Jameton, 1984). It seems, however, that negative feelings associated with moral distress (i.e., anger, frustration, and the like) have been attributed to moral distress in cases where "the right thing to do" was still in question (Hanna, 2004). My assertion is that situations involving differing opinions about the best (i.e., "morally right") course of action evoke discomfort among some members of the health care team, and

that this discomfort is wrongly attributed to moral distress rather than to its actual cause—moral subjectivity.

Nurses' Perceptions of Moral Distress in End-of-life Decision-Making

Ellen Elpern identified situations resulting in high levels of "moral distress" among medical intensive care unit nurses. Nurses identified the following six contexts as causing the greatest levels of moral distress in both intensity and frequency (Elpern, 2005):

1. Continue to participate in care for *hopelessly ill* person who is being sustained on a ventilator, when no one will make a decision to "pull the plug;"
2. Follow a family's wishes to continue life support even though it is *not in the best interests* of the patient;
3. Initiate *extensive* life-saving actions when *I think it only prolongs death*;
4. Follow the family's wishes for the patient's care when *I do not agree* with them but do so because the hospital administration fears a lawsuit;
5. Carry out the physician's orders for *unnecessary tests and treatments* for terminally ill patients; and
6. Provide care that does not relieve the patient's *suffering* because the physician fears increasing doses of

The Mid-Atlantic Ethics Committee Newsletter is a publication of the Maryland Health Care Ethics Committee Network, an initiative of the University of Maryland School of Law's Law & Health Care Program. The Newsletter combines educational articles with timely information about bioethics activities. Each issue includes a feature article, a Calendar of upcoming events, and a case presentation and commentary by local experts in bioethics, law, medicine, nursing, or related disciplines.

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Moral Distress

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pain medication will cause death
(emphases added).

These same themes are repeated throughout the literature on moral distress. In 1981, Davis reported on a variety of contexts in which ethical dilemmas were identified by nurses—the most frequent of which was “prolonging life with heroic measures” (Davis, 1981). Wilkinson’s study in 1988 suggests the same finding, citing the highest occurrence of moral distress among nursing staff was related to prolonging life and performing unnecessary tests and treatments on terminally ill patients (Wilkinson, 1987/1988). Follow-up surveys by both Corley and Omery, et al. continued to confirm these findings through the 1990s, citing specific issues concerning quality of life, do-not-resuscitate decisions, conflicts over what is in a patient’s best interest, and dying with dignity (Corley, 1995; Corley, et al., 2005; Omery, et al., 1995). Finally, Delgado et al.’s study in 2005 on the moral distress in attending physicians and nurses in adult ICU settings found that

nurses experienced moral distress in intensity and frequency more so than physicians—again reflecting the same theme of feeling compelled to provide aggressive treatments at the insistence of others (Delgado, et al., 2005). A conclusion of these three decades of work on moral distress seems modestly summarized by Elpern (2005), who noted: “Moral distress is a serious issue in the workplace and deserves urgent and extended attention.”

With a nod to Elpern’s request, I return to her research in 2005 on the frequency and intensity of the experience of moral distress to offer some analysis. In each of the six examples identified by ICU nurses as an experience of moral distress, there exists language (italicized in the examples above) that either necessitates definition or can only be defined in context. Terms like “hopeless,” “best interests,” “extensive,” “unnecessary” or “suffering” are subjective assessments that require context to flesh out precisely what they mean. A distinction should be made between a true inability of the

The Maryland Healthcare Ethics Committee Network (MHECN) is a membership organization, established by the Law and Health Care Program at the University of Maryland School of Law. The purpose of MHECN is to facilitate and enhance ethical reflection in all aspects of decision making in health care settings by supporting and providing informational and educational resources to ethics committees serving health care institutions in the state of Maryland. The Network works to achieve this goal by:

- Serving as a resource to ethics committees as they investigate ethical dilemmas within their institution and as they strive to assist their institution to act consistently with its mission statement;
- Fostering communication and information sharing among Network members;
- Providing educational programs for ethics committee members, other healthcare providers, and members of the general public on ethical issues in health care; and
- Conducting research to improve the functioning of ethics committees and ultimately the care of patients in Maryland.

nurse (or other health care provider) to act on the patient's behalf when not doing so would jeopardize his or her professional integrity, and the potential lack of clarity and decisiveness on the part of the nurse regarding his or her concrete ethical obligations (Bennett, 2006).

Use of these terms as solely situated within the definitional purview of the nurse seems to suggest an objectivity to terms like "in the patient's best interests" that simply does not exist. This is not to say that health care providers should not question whether the clinical goals articulated by the patient (or by extension his/her surrogate) are reasonable and/or can be realistically achieved based on what is clinically appropriate. Rather, the process of evaluating what a patient would want or what is truly in the patient's best interests often involves subjective assessments about quality of life, beliefs, and values that patients, surrogate decision-makers, and health care providers may not share. In those instances (e.g., following a surrogate decision-maker's wishes to continue life support for a dying patient), health care providers must recognize when moral subjectivity exists, and be helped to work through that moral terrain without misattributing their response to "moral distress."

Conclusions

When examining the precise nature of the term moral distress, the examples identified in the literature revealed instances when there may not have been consensus about the "right thing" to do, and the distress caused by this moral subjectivity was misattributed to "moral distress." Ethics consultants called in to address such concerns need to help members of the health care team recognize that subjective assessments of "right" and "wrong" actions need to take into account the patient's perspective. Without the ability to ascertain how the patient him/

herself defined what is characterized as the cause of moral distress for the health care provider, it is difficult to assess whether there are truly instances when "...one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action." Rather, it may very well be the case that the lack of precision in understanding the moral locus of these subjectively value-laden terms leads to distress. I suggest this is not "moral distress" as defined by Jameton, but rather a discomfort with moral subjectivity.

A re-evaluation of the literature on moral distress may therefore be warranted. A re-evaluation must clearly distinguish between those situations that are properly characterized as moral distress (e.g., a patient is in pain and the nurse is prohibited from administering pain medication for no good reason) and those that reveal a health care provider's difficulty with moral subjectivity (e.g., a nurse disagrees with a surrogate's decision to prolong a dying patient's life based on the surrogate's assessment of what the patient would have wanted). Ultimately, a more precise characterization of moral distress should be sought—that is, a characterization of moral distress that does not smuggle into the concept itself anger or frustration with end-of-life decision-making that is not rightly within the moral purview of the health care provider.

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MOLST IN MARYLAND

Physicians Orders for Life-Sustaining Treatment (POLST) programs currently exist in seven states, and are being developed in several more states across the country. These programs allow persons—particularly those who are seriously ill—to make their wishes known regarding life-sustaining treatments, and to have those wishes communicated and honored across all health care settings. A POLST form differs from an advance directive, such as a living will, in that it reflects actual orders, rather than preferences that inform a clinician’s orders regarding life-sustaining treatments. The primary advantage of a POLST form is that it contains portable orders that travel with the patient across the continuum of care among various health care providers. Recent studies show that a patient’s wishes regarding end-of-life care are carried out more reliably when a POLST form has been completed.

The Maryland version of the form is called MOLST—Medical Orders for Life-Sustaining Treatment—because nurse practitioners can write such orders in Maryland. In the 2011 Maryland legislative session, a bill will be introduced to recognize the MOLST form as a medical order form containing a patient’s preferences for treatment based on the patient’s current conditions and wishes. The MOLST form would be honored in all health care settings, regardless of whether the health care provider had admitting privileges at a particular health care facility. It would replace the Maryland Institute for Emergency Medical Services Systems (MIEMSS) MIEMSS/DNR order form and the Current Life-Sustaining Treatment (LST) Options form.

The MOLST form first requires the practitioner to explain the authority

for issuing it (for example, based on the consent of the patient). The next section records the code status for the patient (i.e., whether cardiopulmonary resuscitation [CPR] should be attempted on scene or when emergency medical services personnel are summoned). Originally, a “do not resuscitate” (EMS/DNR) order allowed only for palliative care. MIEMSS then revised the EMS/DNR order to provide for an aggressive option that allows for other advanced treatments prior to arrest (Option A) and another option for more passive treatments prior to arrest (Option B). In practice, MIEMSS discovered that patients with reversible conditions have been selecting the passive Option B rather than the more aggressive Option A because they did not want intubation. Thus, MIEMSS has deleted intubation as one of the permitted treatments in Option A, creating the current EMS/DNR A (Do Not Intubate—DNI) option. The “old” EMS/DNR Option A (with intubation) forms that have been signed will still be honored by EMS providers.

The second page of the MOLST form contains orders regarding life-sustaining treatments, including artificial ventilation, blood transfusion, hospital transfer, medical workup, antibiotics, artificially administered fluids and nutrition, and kidney dialysis. The intent of the MOLST form is to generate consolidated orders that relate to current treatment issues and preferences. Periodic review of the form is thus vitally important when the patient’s condition substantially changes, the patient is transferred or

The MOLST form would replace the current MIEMSS/DNR order form and the Life-Sustaining Treatment (LST) Options form (formerly called the “Patient’s Plan of Care” form). It meets criteria set forth in the POLST Paradigm.

Visit <http://www.ohsu.edu/polst/> for more information about the POLST Paradigm.

Visit <http://www.dhmh.state.md.us/ohcq/> for more information about the Maryland MOLST form.

discharged, the patient loses capacity to make health care decisions, or the patient changes his or her mind regarding treatments. These events would trigger further review of the MOLST form.

The MOLST form must be kept in the patient’s medical record and transferred with the patient. Only those parts of the MOLST form that relate to a patient’s current treatment condition or preferences would need to be completed. Proper use of the form would require a large, ongoing educational effort. Toward this end, Dr. Steven Levenson has authored a guide on how to use the MOLST form. The plan is to educate all health care providers once the bill is passed by providing train-the-trainer sessions, followed by training conducted by health care provider organizations.

The MOLST form was developed under the auspices of a Maryland Governor’s Council for End of Life Care working group led by Dr. Levenson. Other working group members include Assistant Attorney General Paul Ballard, Dr. Tricia Nay, Bill Vaughan from the Office of Health Care Quality, Dr. Richard Alcorta, and Assistant Attorney General Sarah Sette from MIEMSS.

The draft MOLST form, draft guide, and draft bill are posted on the OHCQ website, at <http://www.dhmh.state.md.us/ohcq/>.

THE PHILOSOPHER'S CORNER: THE PRINCIPLE OF DOUBLE EFFECT

The principle of double effect was developed by Roman Catholic moral theologians in the Middle Ages. It is applied to situations in which it is impossible to avoid all harmful action and a decision must be made about whether one potentially harmful action is preferable to another (Quill, Dresser, & Brock, 1997). It is used to justify claims that the results of an act that would be morally wrong if it were caused intentionally are permissible if the “bad results” were unintended. The principle is often cited to explain why certain interventions at the end of life that hasten death are morally permissible and others are not. The traditional formulation of this principle stipulates that the following four conditions must be met before an act with both good and bad (i.e., “evil”) consequences may be morally justified:

1. The action itself must be good or at least morally indifferent;
2. The individual must sincerely intend only the good effect and not the bad;
3. The bad effect cannot be the means to the good effect; and
4. There must be a proportionately good reason for permitting the bad effect; that is, there must be a favorable balance between the good and the bad effects of the action.

The first condition determines whether the potential action is ever permissible, while the second and third conditions are used to determine whether the potential harm is intentional or unintentional, either as a means or as an end in itself. The fourth condition requires the agent to compare the net good and bad effects of the potential act to determine which course produces an effect of

proportionally greater good (Quill, et al., 1997).

Health care providers may appeal to this principle in morally difficult situations where it is not possible to benefit a patient by an action without at the same time causing harm. The classic example is that of the terminally ill dying patient who is experiencing both great pain and a low respiratory rate. The treatment of choice, morphine sulfate, will alleviate the pain but might also cause respiratory suppression. The clinician’s moral duty to alleviate pain appears to conflict with the duty to protect and preserve life. An argument that the clinician is justified in administering morphine, even if it hastens the patient’s death, is based on the following tenets of the principle of double effect:

1. The action of giving morphine is itself morally indifferent.
2. The intended effect is to relieve the pain, not to suppress the respirations.
3. Respiratory suppression is not the means by which the pain relief is obtained.
4. The relief of pain and the related reduction of suffering combine to provide a sufficiently important reason, or proportionately greater good than the harm that is incurred—respiratory depression and hastened death (Schwarz, 2004).

There are some who question the clinical usefulness of this principle as a guide to ethical decision making (Beauchamp & Childress, 2008). In particular, some clinical experts in palliative care challenge the purported “double effect” of opiate use in terminally ill patients, and describe the likelihood of a secondarily as-

sociated hastened death as an “overblown myth” (Manfredi, Morrison, & Meier, 1998). Indeed, some studies have shown that opioids do not hasten death in terminally ill patients, particularly in patients who are not opioid naïve, due to acquisition of tolerance to an opioid’s respiratory depressant effects (Bakker, Jansen, Lima & Kompanje, 2008; Portenoy et al., 2006). Others caution that “using the [principle of double effect] to justify using opioids to treat pain in dying patients contributes to the belief in the double effect of pain medication, which in turn leads to fear of hastening death and the undertreatment of pain” (Fohr, 1998, p. 316).

Experienced palliative care practitioners recognize that death sometimes occurs secondarily as an unintended though foreseen side effect of opioids used to manage certain refractory symptoms in dying patients, particularly opioid-naïve patients (e.g., in terminal ventilator weaning). Despite the clear legal and moral consensus supporting the appropriateness of such interventions, when a patient dies soon after receiving a dose of opioid, it can be upsetting to the person who administered that last dose. The fear of hastening death has been identified as a primary reason why nurses may be reluctant to provide adequate pain relief to suffering patients (Solomon et al., 1993).

Another concern among critics of applying this principle is depiction of death as being an “evil” to be avoided. When careful titration of medication can relieve symptoms without hastening death, it is not ethically justifiable to forego titration and hasten death. However, not all patients who are dying view death as an evil to be avoided. Magnusson (2006, p. 567)

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Double Effect
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suggests an alternative to the principle of double effect, as summarized here:

In circumstances where the provision of symptom relief is highly likely or indeed certain to shorten a patient's life, it is appropriate to impute to the physician an intention to hasten death. This does not mean that law or medical ethics is committed to acknowledging euthanasia as a routine part of palliative care: it is the surreptitious, undeclared practice of euthanasia that justifies the critique of conventional accounts of palliative care. It is, however, to recognize that physicians must sometimes face the devil's choice: a choice, that is, between relieving suffering and hastening death in circumstances where there is no third alternative and where it is not possible not to choose.

The commonality to both of these methods of justifying hastening death to alleviate suffering is that measures to alleviate suffering are proportionate (i.e., palliative medications are titrated to relieve symptoms), and that there is no other alternative available.

The above article was adapted from the book chapter: Tarzian, AJ & Schwarz, JK (2010). Ethical Aspects of Palliative Care. In M Matzo & D Sherman's PALLIATIVE CARE NURSING: QUALITY CARE TO THE END OF LIFE. New York: Springer.

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ERRATUM

In the Summer, 2010 issue of the Newsletter, in the article "Patients without Proxies—What's Happening in Other States?", we mistakenly referred to University Hospitals Case Medical Center in Cleveland, Ohio as "Case Western Reserve Hospital." Our apologies to Cynthia Griggins, PhD, MA, Co-Director of the Clinical Ethics Service at University Hospitals Case Medical Center and UHCCM staff for this error.

CASE PRESENTATION

One of the regular features of this Newsletter is the presentation of a case considered by an ethics committee and an analysis of the ethical issues involved. Readers are both encouraged to comment on the case or analysis and to submit other cases that their ethics committee has dealt with. In all cases, identifying information about patients and others in the case should only be provided with the permission of the patient. Unless otherwise indicated, our policy is not to identify the submitter or institution. We may also change facts to protect confidentiality. Cases and comments should be sent to MHECN@law.umaryland.edu, or MHECN, Law & Health Care Program, University of Maryland School of Law, 500 W. Baltimore St., Baltimore, MD 21201.

CASE FROM A NICU

Baby Boy Smith is a 2400 gram male infant born at 34 weeks gestation at a small community hospital. His mother is 33 years old, with three other children. Her pregnancy was unremarkable, although she had late prenatal care. The mom reported having a normal prenatal ultrasound at approximately 20 weeks. When she presented in pre-term labor, oligohydramnios (low amniotic fluid) was noted on ultrasound. The infant was delivered vaginally, and required intubation in the delivery room due to poor respiratory effort. Multiple anomalies including bilateral cleft lip and palate, microphthalmia (small eyes), talipes equinovarus (club foot), microcephaly (small head circumference) and ruptured omphalocele (intestines protruding through belly button) were noted at delivery. The infant was transferred to a tertiary care NICU. An echocardiogram following admission revealed large atrial and ventricular septal defects (heart abnormalities). A head ultrasound was reported as normal. On the day of admission, he

was brought to the operating room for primary repair of the omphalocele. He remained intubated postoperatively, and became critically ill with pulmonary hypertension. Rapid FISH testing confirmed suspected Trisomy 13, a genetic disorder in which a person has three copies of genetic material from chromosome 13, instead of the usual two copies.

Following surgery and FISH results, the parents met with the neonatologist, geneticist, and pediatric cardiologist to discuss the baby's diagnosis and prognosis and to develop plans for his care. Recommendations for palliative care were made to the family, and withdrawal of life support was offered. The parents, in particular the baby's father, expressed mistrust in the medical system based on past experiences. The parents discussed strong spiritual beliefs that their baby's future was in the hands of God, whose work was being done by the medical team. The parents expressed understanding that their baby should be comfortable and without pain, but felt that life support should be continued and escalated as needed to keep their son alive. The parents' review of information and case reports on the internet promised hope for a future quality of life for their son that was different from what the medical team described. The parents also expressed concern that there was insufficient medical support near their small town home to adequately care for their son there. They preferred hospitalization in the NICU for their son until he required minimal support and care.

The baby's cardiorespiratory status improved over the first 48 hours of life with high frequency ventilation and nitric oxide, and he was weaned to minimal ventilator support. Over the next two months, he failed multiple attempts at extubation due to significant oropharyngeal secretions and

worsening respiratory distress when off the ventilator. He remained orally intubated on the ventilator, on minimal settings. He developed evidence of pituitary dysfunction with hypoglycemia, metabolic acidosis, and electrolyte instability requiring intravenous (IV) nutrition and fluids in addition to enteral feedings to maintain normal fluid and electrolyte balance. Weight gain was slow but consistent, with no increase in head circumference from birth to 2 months of life. He was maintained on oral morphine for sedation and pain control.

There were multiple family meetings following the time of diagnosis. The parents maintained their position that the medical team should proceed with all life extending care, and their visits became less frequent. The medical team discussed, but did not recommend, a tracheostomy and gastrostomy tube placement as a next step in the care of infants with this degree of illness. The parents declined tracheostomy and gastrostomy placement. They stated on several occasions that further invasive procedures were not in the best interest of their child, but they consistently rejected an end-of-life palliative care approach. The father was at times angry both at the bedside and in family meetings, and vocalized his desire to avoid any further conversations about palliative care, a DNR order, and non-escalation of treatment. The medical team became increasingly uncomfortable giving what they considered to be medically inappropriate therapy, given the diagnosis of Trisomy 13 and the patient's hospital course during the first few months of life. The medical team felt that escalation of treatment and surgical procedures to prolong life such as tracheostomy were not in the best interest of the patient and, at this point, would only prolong pain and

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Case Presentation

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suffering. They questioned the parents' ability to make decisions in the best interest of their child. An ethics consultation was requested to consider whether CPR could be withheld or the ventilator withdrawn based on medical ineffectiveness criteria.

COMMENTS FROM A NEONATOLOGIST & ETHICS COMMITTEE MEMBER

Anticipating the birth of a baby is often a wonderful event for families. Baby gift registries, painting the nursery, choosing daycare providers, planning dates for maternity leave, all events of joyful preparation for a beautiful, healthy infant. Few families have life experiences that prepare them for the possibility that their infant could be born with a life-threatening illness or could die before ever leaving the hospital. In this case, the Smith family experienced an uneventful pregnancy and their prenatal testing was reassuring. There was no warning that anything might be wrong. When labor occurs prematurely, parents are particularly discombobulated, with urgent juggling of jobs, childcare, and finances.

It is no surprise that parents are completely blindsided when their baby is born with serious medical problems. It is, in fact, predictable. On the other hand, obstetrical and neonatal teams are prepared for such unexpected tragedies and have a duty to anticipate the emotional, psychological, spiritual and social needs of families in these scenarios. Services that should be available include personnel trained in how to appropriately deliver bad news, interdisciplinary teams who can immediately address families' needs beyond medical information, and anticipatory guidance for families so that they can brace themselves for this crisis.

Ethically complex decisions oc-

curred in this case from the moment of birth, long before the issue of a tracheostomy was raised or an Ethics Consultation requested. The Smith family—and the obstetricians—had no warning that the newborn would have a life-threatening condition. He was urgently transferred to a regional hospital, a transfer that separates infants from their parents and often involves hours of commuting for the family. Whether to transfer a baby with suspected Trisomy 13 to a regional hospital may arguably not be in the best interest of the infant or family. Palliative care from the moment of birth would be another option. Parent surprise about the infant's condition and community physician discomfort with making complex diagnoses or limiting interventions often prevent early consideration of palliative care. This may have led to Baby boy Smith's transport in this case.

The neonatologists at the regional hospital seem also to have been taken by surprise by the diagnosis of Trisomy 13, a condition which has a median survival time of 7-10 days and a 95% mortality in infancy (Rasmussen SA Peds 2003). Gastroschisis repair was completed on the first day of life, presumably prior to confirming the important diagnosis of the life-limiting syndrome, and likely when the mother was still an inpatient at another hospital. We do not know if the decision to perform gastroschisis repair—a procedure which is often not emergent—was weighed against the option to provide comfort care only for this infant with a severe genetic syndrome. We do know that the medical team did not request an Ethics Consultation at that time.

Neither the decision for neonatal transport nor the decision for gastroschisis repair may have been presented to the family as ethically complex options. Physicians are profession-

ally obligated to provide medical treatment to newborns when diagnostic and prognostic uncertainty is very high, as it may have been in the first days of this case. But they feel similarly ethically obligated to delay non-emergent surgeries when a severe, life-limiting genetic syndrome is part of the differential diagnosis. When this kind of thoughtful analysis and clear communication with the family does not occur, the family often finds it difficult to reconcile with the medical team's threshold between "doing for" and "doing to." Parent mistrust of physicians, identified as an important barrier in this case, is only enhanced when physicians initiate a complex treatment course and then quickly ask parents' permission to abandon it.

That parents find comfort and hope in their religious beliefs is common during their child's critical illness (Boss, 2008; Robinson, 2006). The family in this case indicated that they believed their baby's care was in God's hands; it is unclear how the medical team explored the sources and boundaries of this belief, or whether a chaplain was called to navigate physician-family conversations about suffering, hope, and quality of life. A time-limited trial of intensive care, with a plan to allow natural death to occur barring substantial improvement, can be acceptable to some families with similar belief systems.

The medical team experienced moral distress in their care of the Smith family, particularly when it seemed that this family who "wanted everything done" for their son, did not want him to come home. Apparently both the parents and the medical team agreed that a tracheostomy and g-tube were not in the infant's best interest, and the medical team should feel good about their ability to align these goals. The conflict revolves around how the infant is going to die: the medical team

wishes to withdraw life support now, and the parents want the infant to continue to live in the NICU indefinitely. Staff moral distress, which often precipitates Ethics Consultation, requires direct acknowledgment and intervention by leadership. It appears that in this case, moral distress was only aggravated by physicians who offered CPR to the parents. Limiting painful procedures, maximizing treatment of pain and agitation, helping to engage the family during their visits in the NICU, and a plan to forgo medically ineffective surgeries, reintubations, or CPR attempts, is an ethically defensible path. This could promote infant quality of life, offer more time for the family to bond and grieve, and could diminish staff distress.

That this case is presented with extensive information about the family's goals and motivations—but minimal information about the medical team's personalities or motivations—serves as a reminder that such “difficult” cases are often viewed as isolated problems with particular families. Many of these “difficult” issues are predictable system problems that occur when communication and navigation of ethically complex cases is not routinely emphasized in medical training, maintenance of board certification, or career advancement. Ethics consultations are generally called when prolonged clinical scenarios have reached a crisis of communication breakdown and dysfunction. The meaningful impact that such crisis consultations can have on family outcomes and future physician decision-making in similar scenarios is unclear.

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COMMENTS FROM A NURSE ETHICIST

Parents think about their responsibilities as parents which includes not just caring for and about their new baby, but also a duty to support him and do what is best for him. In the NICU, parents are forced to share their parenting responsibilities with members of the health care team. The lack of trust between the parents and the medical team is in many ways the central issue of this case. Without trust, parents will not believe the team respects them and may not believe what the team says, as is evident by these parents' hopes for a better future based on what they have read on the internet. The parents have acknowledged limits to the interventions they feel their son should endure, namely the tracheostomy and gastrostomy tube. When the team questions the parents' ability to make decisions in the best interests of their son, it is evidence that the team does not trust the parents any more than the parents trust them.

When they trust health care providers, parents are more able to accept information from them. Parents interpret one meaning about the baby's condition based on what they see, and that meaning in this case seems to be contradicted by the information from providers, which represents a different interpretation of the baby's condition. Parents struggle with their hopes for a better future for their son and the

reality of his condition in the NICU. In a sense, there is a reality they want juxtaposed against a reality the health care team believes they must accept. In fact, the parents were given a grim prognosis early on in this little boy's life, and yet thanks to technology and the good work of the health care team, he is still alive two months later. Why would any caring parent give permission to stop treatment when clearly it has allowed their son to live?

While physicians who believe a treatment is ineffective may have the legal authority in Maryland to withhold procedures, including CPR, in this case, such an approach would reinforce the parents' perceptions that physicians cannot be trusted. Yet the mounting moral distress of the professional caregivers cannot be ignored. Not only do physicians and nurses in particular have to witness the suffering of this infant, they bear the burden of providing on-going care. Routine medical care for this infant involves daily interventions that are painful and uncomfortable with no real expectation that those interventions will change the outcome for this infant, namely that he cannot live outside the ICU and his complex constellation of anomalies virtually guarantees that he will die before ever being stable enough to return to a neonatal unit closer to where the parents live, let alone for them to care for him at home.

The central dilemma in this case is how to reconcile the reality that the parents have mutually inconsistent goals – they wish their son to live yet believe placement of a tracheostomy is not in his best interests, and yet in order for him to live he needs a more stable airway. Forcing the parents to consider a DNR approach, or comfort care only, in the absence of any success at getting them to trust the team perpetuates the illusion that the parents have a choice, when in reality their choice is ultimately not about continuing treatment, but about

Case Presentation

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planning for how they want their son to die. Constantly asking parents to consider a choice where no real choice exists would be confusing for anyone, let alone parents who do not trust you.

Parents need to believe that physicians present options of limiting treatment because they are sincere and compassionate, basically that they care about the baby and the baby's family. Anger and frustration on the part of the health care team do not convey caring. Demonstrations of grief or sadness on the part of providers could send a powerful message to parents, namely, that the doctors and nurses genuinely care about their son. Trust inspired by a caring context will promote these parents' confidence in the information and the plan for the baby. Rather than ask repeatedly about DNR and referring to the plan as end of life care, a more useful approach might be to not ask explicitly for their permission but lay out a plan for extubation and no reintubation.

Rather than DNR, health care providers should discuss why extubation to CPAP, for instance, is a step toward one of their stated goals (i.e., getting him closer to home) and then discuss why putting the endotracheal tube back is not consistent with the overall goal for him. Instead of talking about what will not be done, focus on what will be done. Constantly offering the parents a choice or seeking their permission implies a choice when in this case there is no real choice about saving this little boy's life.

It is ethically defensible to extubate with a plan not to re-intubate. It is based on the burden of intubation and the standards of care for neonates. Refusal of a tracheostomy means the parents are in effect saying if he needs a tracheostomy to live, the burden is too great. For health care providers

to keep hammering away and asking them to agree to a DNR order puts an unnecessary burden on the parents. They are making their wishes clear and it is up to the health care team to support them and explain what their choice means. The biggest challenge is to give parents the feeling of control, of the sense of their making a parental decision without asking them to make a medical decision about the efficacy of any given treatment.

Language is crucial. If the baby has respiratory distress after extubation (do not say "fails extubation") then the team will provide comfort measures to ease the discomfort and work of breathing. The baby will continue to receive care and attention from the doctors and nurses, but addressing any respiratory distress cannot include replacing the endotracheal tube. Rather than say the team will not resuscitate the baby, the team should emphasize that if the baby deteriorates, they will allow a natural death.

It is crucial in this case, if possible, to avoid a resuscitation scene. To make a plan with the parents to be present for extubation with family and staff there to support them and reassure them that their son will be comfortable and that the team will be there to care for their son, but not to put him back on the ventilator. If the baby deteriorates to the point where he meets the criteria for resuscitation, physicians may and in this case they have an obligation to exercise their clinical judgment and stop a resuscitation when they feel it is not achieving the goal. The team in this case should not have to "prove" a resuscitation will not work. One of the challenges in this case is to prepare the nurses for what to do when the patient meets criteria for CPR. That is a challenge because in the neonatal setting, expert practitioners are trained

to intervene to prevent the code from happening and in effect begin an ICU resuscitation before the dramatic, TV-style resuscitation is needed.

Members of the health care team need assistance from ethics and palliative care to reframe their thinking about actions. To be a good ICU nurse or physician means to prevent the need for resuscitation. In this case, to be a good ICU nurse and physician may be to allow the baby's condition to deteriorate to where he meets resuscitation criteria and then gently, carefully and skillfully support him without intervening to stop nature from taking its course.

Ethicists debate appropriate theories and models to use to resolve ethical dilemmas such as the ones faced by the parents and health care providers in this case. Parents do not identify ethical theories or models that are helpful to them as they struggle to make meaningful choices in the face of uncertainty, suffering and loss. The parents in this case do not need help with decision making. They need help feeling they are good parents even as their baby dies in the NICU. They deserve respect as parents.

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CALENDAR OF EVENTS

JANUARY

- 11** (12-1:30 PM) Tony Black, MD, Sheila Hutzler-Rives Memorial Lecture, Berman Institute of Bioethics Seminar Series, 615 N. Wolfe St., Baltimore, MD, W3008. For more information, visit <http://www.bioethicsinstitute.org/>.
- 11** (12-1:30 PM) David Brendel, MD, PhD, “ScattergoodEthics Program” lunch presentation. Penn Center for Bioethics, 3401 Market Street, Room 321, Philadelphia, PA. RSVP to: spaebh@mail.med.upenn.edu. Call 215-898-7136 for more information. Also visit <http://www.scattergoodethics.org/>.
- 14** (8:15 PM) The Value of Life, lecture by Mr. S. Ramachandran, St. John’s College, Francis Scott Key Auditorium, Annapolis, MD. For more information, call 410-626-2539.
- 21** (8:15 PM) Wealth, Virtue and Corruption: Adam Smith's Moral Philosophy, lecture by Mr. Lauren Brubaker. St. John’s College, Francis Scott Key Auditorium, Annapolis, MD. For more information, call 410-626-2539.

FEBRUARY

- 10** (5-7 PM) “Health Care Disparities and Health Care Reform,” Professor Emeritus Frank McClellan from Temple University Beasley School of Law. Part of the Health Law Reform Speaker Series at the University of Maryland School of Law, 500 W. Baltimore St., Ceremonial Court Room (160E). Talk followed by reception. Contact: Virginia Rowthorn (vrowthorn@law.umaryland.edu).
- 14** (12-1:30 PM) Jeffrey Kahn, PhD, MPH, Berman Institute of Bioethics Seminar Series, 615 N. Wolfe St., Baltimore, MD, W3008. For more information, visit <http://www.bioethicsinstitute.org/>.
- 28** Managing Electronic Communications in Professional Practice: Emerging Ethical Challenges and Risk-Management Implications. Workshop presenter Frederic Reamer, Ph.D. Rhode Island College School of Social Work, Mt. Washington Conference Center, 5801 Smith Ave., Suite 1100, Baltimore, MD. For questions, contact Linda Friend at 443-923-2802.
- Feb. 28-**
Mar.1 The Presidential Commission for the Study of Bioethical Issues meeting (open to the public). For information on location, webcast, and to obtain transcripts, visit <http://www.bioethics.gov/meetings/>.

MARCH

- 5** Valuing Lives, a one-day conference in New York, NY. Contact Ben Sachs for more information: sachs@nyu.edu, 212-992-8686.
- 18-20** Bioethics—More Personal or More Global? National Undergraduate Bioethics Conference at Duke University, Durham, North Carolina.
- 31** (5-7 PM) “Health Care and Cost Containment.” Health Law Reform Speaker Series at the University of Maryland School of Law, 500 W. Baltimore St., Ceremonial Court Room (160E). Talk followed by reception. Contact: Virginia Rowthorn (vrowthorn@law.umaryland.edu).

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