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Navigating the Liminal State Between Life and Death: Clinician Moral Distress and Uncertainty Regarding New Life Sustaining Technologies

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Barg, *et al.* describes the lack of a culturally scripted role for existence in a liminal state following LVAD implantation and how that creates uncertainty for patients at this borderland between life and death. In this commentary, I shift the focus to clinicians who feel similar uncertainty surrounding the treatment of dying patients with LVADs and other new technologies such as Extra-corporeal Membranous Oxygenation (ECMO).

I do so by referencing my own qualitative studies on physician attitudes surrounding end-of-life decisions (Dzung et al. 2015). I found that physician trainees frequently experienced moral distress, defined as the inability to act in accordance with one's ethical beliefs due to hierarchical or institutional constraints, regarding therapies that they believed to be futile at the end-of-life (Dzung et al. 2016; Jameton 1984).

Respondents in these interviews described distress over the use of new technologies that they did not feel ethically or clinically equip to handle. This internal medicine resident stated:

“...We did not know how to run a code because [they] had an LVAD. Is there a pulse? The nurse [said], no there isn't a pulse. We did not know what to do. We could not run a code. It is a totally different situation...it is really awful.”

LVADs and ECMO create uncertainty around dying that can engender anxiety amongst physicians. This is manifested through moral distress regarding the provision of burdensome or futile care and through uncertainty surrounding the definition of death, as described by this intensivist:

“...So I'm sure I have a dead patient on ECMO, but the pump still flows. They may be asystolic...so you have a patient on ECMO...who you are almost certain has an anoxic injury with cerebral edema, but you can't do a brain exam on them because you can't do an apnea test, because they're on ECMO circuit. So declaring brain death on a patient on ECMO is one of the hardest things...Ultimately what it took in this patient was, we consulted ethics, and basically we had to...write notes that we believed the patient was clinically dead, which was the weirdest thing to write. Based on what? It probably went on for 48 hours longer than it should have because we were like, 'this is such a weird situation, what do we do with this?'”

One study corroborates this lack of consensus regarding defining brain death in a patient on ECMO (Kreitler et al. 2015). This uncertainty further contributes to moral distress:

“...I think what probably bothered everybody most...is that final 48 hours where we took it too far, that we didn’t call it sooner. I think that’s probably a failure to diagnose death...the distress and what makes people walk away not feeling good about what we do. It’s that we put people through, for all of this, for LVADs, for ECMO, that we push it too far. I think that’s what weighs our nursing staff...we lose nurses from this ICU unlike any other area...”

Changing expectations of new technologies promote liminal states between life and death

Berg *et al.* cites Sharon Kaufman in describing the process whereby new technologies become “normal”, driven by a salvation ethos that assumes that new technologies are inherently beneficial (Kaufman 2015). These technologies transition from being experimental towards becoming the standard of care for a wider variety of indications that it was initially designed for. Our understanding of the ethical and social implications of these technologies in redefining death has lagged behind clinical progress and uptake of these new technologies.

The history of ECMO reflects this salvation ethos. ECMO has primarily been used for acute respiratory distress syndrome, bridge to transplant or LVAD, or post myocardial infarction or cardiac surgery. However, a new indication for ECMO is as an adjunct to resuscitation during in-hospital, and even out of hospital cardiac arrest (“ECPR” or “crash to ECMO”) (Chen et al. 2008; Sakamoto et al. 2014). As an illustration of this “technological creep”, the development of these programs may be unplanned. I asked a cardiologist at a major American cardiac care center whether they had a “crash to ECMO” program:

“With the H1N1 flu epidemic, [ECMO] became very facile...you could put it on easily [for other indications]...it’s an intermediate that takes us deeper into longer supportive care...If the only support you had was long-term support like a HeartMate (LVAD), then you’d say, ‘well the patient is in renal failure and vegetative and therefore the patient is not a candidate’. It’s very clear. But now you can put ECMO in and it’s non-surgical. Technological advances have really blurred the lines...So do we have a specific crash to ECMO program? No. But...we have cardiologists who are tilted towards intensive care and acute care. We have surgeons readily available. So in that sense, yes, I guess we have a ‘Crash to ECMO’ program”.

Given the fervor by which new technologies are embraced, one can imagine that one day, ECPR will become a standard of care. In anticipation of this future, we must preemptively grapple with the ways that these technologies change the definition and experience of death and dying.

Strategies to address ethical and social challenges surrounding death and dying with new technologies

In order to accomplish this, several strategies should be adapted for new technologies that create liminal states around death.

1) Medical education for non-specialists

Given the likelihood that these technologies will become more widespread, it is increasingly likely that non-specialist clinicians will encounter these devices in their clinical practice. Prioritizing clinical and ethics education of non-specialist clinicians will help mitigate potential confusion and distress surrounding the care of these patients.

2) Develop strategies to address palliative care and advance care planning (ACP)

Palliative care research and education should be prioritized. This resident describes the confusion surrounding ACP in these patients:

“So we had all of this technology...it sets up a totally different expectation that all these people who had been coded at outside hospitals who had died in effect, [are] now are being crashed to ECMO. Now this person does not have a heartbeat. They’re not breathing on their own. How do you even approach discussions of DNR/DNI at that point?”

One challenge is the way LVADs and ECMO intrinsically function in a way that is incongruous with certain aspects of palliative care and ACP.

“If you have one of these devices, up until the point you’re transitioning to comfort care...its full core press...it’s a strangely binary thing, like once you’ve stepped in to the world of mechanical circulatory support, it’s like your sort of checking all the boxes [for aggressive care], ‘yes’, at least for the time being.”

Given this uncertainty amongst physicians, it is not surprising that the patients in Berg *et al.* (p18–19) described unsatisfying physician responses to queries regarding death with an LVAD. Palliative care practitioners, ethicists, surgeons and intensivists could begin this process of addressing palliative care by coming together to establish consensus statements on how to address end-of-life and palliative care in patients on ECMO or with LVADs.

3) Recognize different moral economies surrounding end-of-life care and how that might contribute to moral distress within inter-professional teams

A further challenge that new technologies pose is the blurring of lines between surgical and medical subspecialties, whereby medically trained physicians increasingly encounter quasi-surgical devices such as ECMO and LVADs:

“I think that what patients probably don’t recognize that they’re getting into is they’re sort of tipping over into this sort of surgical covenant...if you’re going to do this you’ve got to be in it to win it...”

Surgeons bring cultural norms unfamiliar to medically trained physicians, such as the “rescue credo” of “first, do not let the patient die” and the surgeon’s covenant, an unspoken

commitment binding the surgeon and patient to a total commitment to success regardless of adverse outcomes (Buchman 2010; Buchman, Cassell, and Ray 2002).

Joan Cassell described *moral economies* that differ between surgeons and intensivists, where the primary goal of the surgeon was to “defeat death” whereas intensivists prioritized an ethics of scarce resources and quality of care (Cassell 2005). These vastly different perceptions and end of life care goals resulted in conflict and miscommunication due to “incompatible views of medical reality [where] the other’s viewpoint and behaviors appear not only misguided but *immoral*”.

Individual actions and behaviors are influenced by individuals’ worldviews and beliefs. Systemically-based interventions that focus on recognizing and reconciling these different moral economies amongst inter-professional teams would not only improve quality of care, but also mitigate conflict and moral distress.

4) Developing ethical framework and clinical consensus guidelines on defining death in patient on ECMO and with LVADs

There is a need to develop clear clinical consensus guidelines on how to declare brain death in patients on these new technologies. As these technologies become more common, developing frameworks for diagnosing death and exploring the ethical implications of technologies that create liminal states become critical. As Berg *et al.* and my research demonstrates, failure to do so place the well-being of patients, caretakers, and clinicians at risk of psychological harm and distress.

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