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CE Ethical Challenges and Implications of Deactivating Mechanical Circulatory Support for Patients With Preserved Cognitive Function

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Walking onto an intensive care unit can be almost otherworldly. Nurses, gowned, gloved, and masked, hover like anonymous overseers, busily moving from one human form to another. These forms, the patients, float silently on shifting air mattresses, tethered to machines of various shapes and sizes, the sounds and lights amplifying a sense of measured urgency. Some patients have just arrived, and others, consciously or unconsciously, have resided here for weeks.

The goal of this fastidious operation is not wholly apparent. Is it to heal, this goal? Or simply to sustain or prolong life? One might assume from the frenzy of nursing activity and array of machines that most of the forms are reasonably closer to death than to life, beating hearts not excluded. In the limbic realm of intensive care, this truth—made less evident by our extreme efforts to evade it—is our most bewildering one: eventually, death is certain.

Nonetheless, the nurses go to great lengths, at a wearying pace, to preserve whatever life forces remain.

Case Part I

Mr B, a 36-year-old mathematics teacher and father of 2 children, assumed he would be admitted to the progressive cardiac care unit, tolerate a few days of aggressive diuresis, and be discharged home a few days later and several pounds lighter. But, unbeknownst to him, this time would be different.

Diagnosed 2 years ago with New York Heart Association class III-IV non-ischemic heart failure with reduced ejection fraction, Mr B lived independently, worked full-time, and coparented his 2 young boys. In recent months, however, he noticed that activities such as maintaining his apartment and keeping up with his energetic toddlers had become increasingly difficult. He experienced worsening symptoms—shortness of breath, anorexia, epigastric pain, and edema. He could not have anticipated that, within the course of a week, his body would be reduced to an attenuated form reliant on multiple modes of mechanical support—an unrecognizable version of his former self.

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Mr B was much sicker than he had perceived himself to be. By the time he was admitted to the hospital, he was no longer appropriate for the intermediate care unit. A flurry of tests and procedures ensued, and within hours of his admission to the intensive care unit, Mr B had consented to an expedited advanced therapy evaluation. When it was clear that his heart had become too weak to support his body, his care team proposed placement of a left ventricular assist device. Given his precipitous decline and the degree of cardiogenic shock, few other options remained, and so Mr B agreed to undergo this life-saving procedure.

An Illusion of Immortality

The advent of mechanical circulatory support (MCS) has made it possible for patients with end-stage heart failure to move farther along the disease trajectory in pursuit of advanced therapies such as durable ventricular assist devices and heart transplantation.¹⁻³ Although these therapies are intended to provide patients with better quality of life and longevity, postoperative courses often require additional layers of temporary mechanical supports and life-sustaining treatments (LSTs) such as mechanical ventilation, extracorporeal membrane oxygenation, and dialysis, which contest and often redefine our perceptions of the biological limitations of the human body and clinical thresholds for patient suffering.³⁻⁶ Increasingly complex clinical cases prevail, challenging both the limits of medical and mechanical management and our attitudes surrounding the “locus of decisional authority” when it comes to end-of-life decision-making.^{1,6,7-9} Nurses in particular are charged with the immense responsibility of executing the delivery of maximal care while tempering the illusion of immortality it creates, often when patients are most vulnerable.

Case Part II

Everyone says Mr B is making progress, but I can tell by the look on his face that he is too close to the struggle to appreciate his recent strides. The mattress droned as I heaved his fluid-filled legs onto the bed. He had just walked 40 steps down the unit corridor but, limp and winded, Mr B appeared as though he had run a marathon. He reported pain all over, a pain that no longer corresponded to a specific device or drain, wound or incision and was more like a dense fog. His electronic

medication administration report revealed that an increased focus on pain medication had crept in alongside it.

His eyes were closed beneath a furrowed brow, and he nodded his head side to side as if in silent refusal. I placed my cool hand on his damp forehead, inviting him to speak. Mr B verbalized that he is tired and doesn't want to suffer anymore. He said how hard everything has become: eating, walking, sleeping, breathing. Even urinating was impossible. He spoke about the constant pain and discomfort and about how he is tired and tries to rest but cannot sleep. He acknowledged that he doesn't want to die but doesn't know how he will manage to carry on.

Informed Decision-making

A key component of ethically grounded care involves honoring the ability of patients with decisional capacity to make informed decisions that reflect their values and preferences. The opening provision of the American Nurses Association's *Code of Ethics for Nurses* (2015) outlines a nurse's professional duty to respect a patient's inherent dignity and autonomous choice.¹⁰ Likewise, the process of informed consent informs clinicians' responsibilities toward this end.

Decision-making Capacity. The informed consent process is predicated on a patient's decision-making capacity: the capacity to state the risks and benefits of a particular treatment and to weigh and balance these risks as they apply to their own life, in accordance with personal goals and values, at a particular time.^{11,12} Concerns surrounding capacity often arise when patients lose capacity to make medical decisions for themselves. In these instances, decisions may be time sensitive or emergent, requiring clinicians to rely heavily on surrogate decision-makers to demonstrate “substituted judgment” (ie, act as a conduit for a patient's wishes and values to guide care decisions), a task that can pose significant challenges during the decision-making process and may ultimately affect the patient's experience, clinical outcome, or both.^{2,11} The Figure outlines a mnemonic to facilitate rapid evaluation of the 4 “core abilities” of the patient—(1) choose and communicate, (2) understand, (3) reason, and (4) value—that are required for adequate decision-making capacity.¹²

Patients *with* capacity can pose equally significant challenges to the process of complex

Choose and Communicate – “Can the patient communicate a choice?” Patients must be able to choose from among the options including nontreatment.

Understand – “Does the patient understand the risks, benefits, alternatives, and consequences of the decision?” Information that is relevant and meaningful to the patient’s decision-making must be understood.

Reason – “Is the patient able to reason and provide logical explanations for the decision?” Assess if the patient is able to understand consequences and alternatives to proposed treatment.

Value – “Is the decision in accordance with the patient’s value system?” Clinicians must be aware that a patient’s values and goals may change over time.

Emergency – “Is there a serious and imminent risk to the patient’s well-being?” If the patient’s need for mechanical circulatory support is emergent, consent may be waived.

Surrogate – “Is there a surrogate decision-maker available?” Identifying a health care agent when the patient has decision-making capacity is an important exercise of autonomy.

Figure: CURVES, a mnemonic for assessing decision-making capacity and providing emergency treatment in the acute setting. Adapted from Chow et al.¹²

decision-making. For example, patient requests to deactivate MCS may be perceived as emotionally driven, premature, or both, causing surgeons and members of the care team to question the integrity of the patient’s autonomous choice.¹³ Jodi Halpern brings this concern into focus: “The problem for people who are suffering is not just that they cannot imagine future goals that are several steps away, but that they also lack enough security and comfort to feel a sense of ongoingness into the immediate future. Without the sense that life is currently tolerable . . . there is no reason to form any intention other than to bring about the termination of one’s suffering—and one’s existence.”^{11(p112)} Consequently, clinicians must respond to patient requests to deactivate MCS and ensure, in collaboration with members of the interdisciplinary team, that patients are not only adequately informed and supported but also of sound mind and spirit.

The Process. The process of informed consent is a dynamic, multidirectional exchange of information among key stakeholders that facilitates and upholds a patient’s autonomous decision to pursue or forego a medical therapy or intervention after a thorough explanation of known risks and benefits and a discussion of possible alternatives and predicted outcome based on specific patient criteria in comparison to similar clinical profiles.^{12,14,15} In its most basic form, informed consent can be reduced to a series of transactional exchanges. When executed properly, however, informed consent evolves and is central to the process of informed decision-making (Table 1).¹⁴ Ideally, this process takes place across the care continuum, beginning as soon as the need for MCS is identified and before MCS is placed—by way of informed consent—and continuing after

placement.^{13,14,16,17} Ongoing, proactive, and transparent care discussions underscore the potential for clinical fluctuations and the importance of making space for patients and surrogates to call for adjustments or changes to the care plan.^{14,16,17} Multidisciplinary collaboration helps augment patients’ and surrogates’ understanding, and patient-centered care approaches aid us in maintaining a necessary balance between expert medical guidance and patient-specific goals and values.^{1,14,15,17}

Challenges for Nurses

As nurses, we share information in some way during almost every patient interaction. But what does “fully informed” mean for a patient who is agreeing to have their chest surgically opened, their heart and lungs mechanically supported, and their capacity to participate in their care momentarily suspended? How can we exercise the various dimensions of our nursing role to help prepare patients for the potential rigors of a complicated postoperative course? How do we convey, with accuracy and sensitivity, the hypothetical yet not uncommon scene of oscillating clinical stability, repeat trips to the operating room, and seemingly endless diagnostic tests and procedures—not to mention iatrogenic byproducts such as unconsciousness, pain and discomfort, weakness, and malnutrition, which can result in a lack of patient autonomy and an existential loss of self? How do we work to legitimize and maintain nurses’ critical role in the processes of informed consent and complex decision-making?

Case Part III

I felt his eyes following me as I logged onto the computer, emptied my pockets of

Table 1: Elements of the Informed Decision-making Process About MCS^a

When to Engage in the Process

When possible, prior to implantation of device or as soon as feasible
 Have frequent, ongoing, proactive discussions that account for fluctuations in clinical course and potential for change in patient values, goals, or prognosis

Who to Involve in the Process

Key disciplines and specialties such as surgery, cardiology, nursing, social work, palliative care, chaplaincy, possibly ethics
 Include patient/family/caregivers/health care agents in ongoing discussions

What to Include in the Process

Elicit patient preferences, goals, and understanding of the patient’s current condition and need for MCS
 Proactively assess and document patient preferences regarding goals of care, particularly with respect to MCS, including preferences for limitations of treatment
 Have comprehensive dialogue, including benefits and risks, likelihood of clinical improvement, psychosocial aspects of life and care with and without MCS, and potential end-of-life care, including MCS deactivation
 Educate patient with decision-making capacity on the importance of advance care planning and encourage them to identify and document preferences and goals and share information with family or a health care agent¹¹
 Encourage patient to designate and document a health care agent in the event the patient loses decision-making capacity

How to Engage in the Process

Conduct an ongoing assessment of patient decision-making capacity prior to initial discussions and periodically thereafter, especially when there is a change in mental status
 Communicate evidence-based information in a clear, concise manner
 Assess the patient’s understanding of information, documenting and re-evaluating as new information emerges
 Ensure you understand and respect patient preferences
 Conduct ongoing surveillance for evidence of ethical conflicts, moral distress, or ethical dilemmas by patient, family, or health care team
 Proactively involve ethics consultants

Abbreviation: MCS, mechanical circulatory support.

^a Adapted from Boothroyd et al.¹⁴

his medications, and scanned his identification bracelet. “I don’t know how much more of this I can take,” Mr B said as I moved my hand to rest atop his hand. I had cared for Mr B many times and was used to his shifting moods. Some days were easier for him than others; today was different still. He began to ask questions about the withdrawal process—What would it entail? How long would it take for him to die? Would he suffer? I answered his questions honestly and directly. “I don’t want to die, but I don’t want to suffer,” he said, suddenly reminding me that some states of being are worse than death.

Cross-Purposes: The Aim of Perspective Taking

To navigate the psychosocial matrix of informed decision-making, interdisciplinary team members must pause and acknowledge how differences in professional scope, proximity to suffering, and personal philosophies might impact how each team member interprets and responds to a capacitated

Table 2: E-PAUSE^a

Pause, notice, and reflect to empower ethical competence and resilience.

- E** - Ethical context
- P** - Perspective taking
- A** - Ask questions
- U** - Utilize resources
- S** - Stand up and speak up
- E** - Empower my ethical practice

^a Reproduced from Rushton et al¹⁸ with permission from Johns Hopkins University.

patient’s call to reevaluate and potentially alter the trajectory of care (Table 2).¹⁸ This exercise in perspective taking must also be applied to patient and surrogate.

The Patient. Although Mr B’s body is fully supported by LST—his lungs, intermittently, by a ventilator; his heart, by right and left ventricular devices; and his kidneys, by continuous dialysis—his brain has remained intact, and so, unlike many critically ill patients, Mr B is attuned to the sobering reality that his

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existence hinges solely on the machines whose constant thrum envelops him.

His best-case scenario of the *prospect*—not even the promise—of dual-organ transplant seems like a far-flung fantasy, and the idea that he might have to remain in the hospital for months, perhaps up to a year or more, to achieve it is equally inconceivable.^{11,13} On the other hand, he understands that the alternative is death. Although some may consider death to be his worst-case scenario, Mr B is beginning to wonder whether it might not be the more humane path, and he is curious to know how one goes about making space for it.

The Surgeon. Although the patient is closest to the illness experience and bears the primary physical and emotional burden, surgeons are positioned at the helm of care. They consider themselves, and are considered by others, to be the stewards of the mechanical technology and, by extension, its recipients.¹⁹ The patient-surgeon relationship is one of physical intimacy. To cut through a patient's skin, muscle, and bone to reveal their beating heart is like holding their life source in the palm of one's hand. It is deliberate yet risky, raw yet restorative, and only a surgeon can understand what it feels like to know a patient in that way, if only to put them back together again.

Many surgeons perceive a patient's consent to undergo implantation of mechanical support as contractual, a commitment that supersedes the stark parameters of informed consent and the less-than-obvious language of advanced directives. This phenomenon is referred to as "surgical buy-in."⁴ Although surgeons understand that each postoperative course will differ on the basis of each patient's unique circumstances, their commitment to producing a favorable outcome does not waver. Not surprisingly, it follows that "physicians favor themselves, more so than patients and surrogates, as the locus of decisional authority for initiation and discontinuation of [veno-arterial extracorporeal membrane oxygenation]."^{19(p284)} What this shared attitude fails to accommodate, however, is the patient's right to choose in accordance with their preferences and their lived experience with MCS.

The Nurse. The depersonalization of mechanical medicine has threatened to reduce our patients to forms and us nurses to automatons of care. Indeed, sizable elements of standardization, coordination, and routine define the work of nursing; these qualities

elevate the practice and ensure that all patients receive optimal care. Less obvious are the nuanced, artful, and human elements of nursing that reach beyond the physical realm to include compassionate care, clinical humility, and patient advocacy.

Sentinels of patient care, nurses base their work on evidence yet are deeply intuitive.⁹ They witness up close the physical and emotional impact of illness, provide care and comfort to the ailing, and cultivate trust amid uncertainty. They assist patients and care teams in weighing and balancing the benefits and burdens of treatments and are prepared—often well before others—to acknowledge the evidence of a failing body and to honor a patient's desire to discontinue mechanical therapies and allow natural death.

Nurses are devoted to fulfilling the expansive yet essential demands of their role, an endeavor that requires physical and emotional fortitude. Driven by a responsibility to uphold their code of ethics, nurses frequently place the needs and welfare of their patients before their own, a practice that can erode their moral resilience.⁹ No matter how much experience one has, no matter the extent of one's exposure to suffering or knack for resilience in difficult times, nurses struggle to negotiate their own value strain and uncertainty surrounding decisions to discontinue LST, especially for patients receiving MCS who have the capacity to make decisions that will result in death.⁹

Elements of Moral Suffering

Moral suffering, "the anguish experienced in response to moral harms, wrongs or failures and unrelieved moral stress,"^{20(p61)} emerges when clinicians witness, contribute to, or cause any of a variety of morally distressing outcomes—a process that involves erosion of moral integrity.

In a world of thrumming technology and contrasting care perspectives, how do clinicians create space for constructive dialogue and principled action to anticipate and alleviate moral distress that arises from complex decision-making? How, as participants in a care cooperative comprising differing views, personal philosophies, and professional orientations, can members of the care team work together to acknowledge and uphold a patient's right to choose, especially when the choice conflicts with expert medical guidance and will result in certain death? How

do nurses maintain a sense of moral wholeness while anticipating, orchestrating, and implementing withdrawal of LSTs?

To gain insight into these questions, one must first explore which elements cause distress or suffering when confronting a request from a cognitively intact patient to deactivate MCS. Is there something about the act of turning off a machine that makes this care choice feel ethically murky? For example, do we perceive a decision by a patient with heart failure to deactivate their left ventricular assist device as different from that of a patient with cancer choosing to forego a clinical trial? Are these choices, in fact, different? Could the former be considered an irrational death wish and the latter a display of rational acceptance? What factors might influence our perceptions of the ethical integrity and permissibility of each and our ability to honor a patient's decision to allow death?

Ethical Permissibility. Consensus exists, by way of ethical and legal position statements, that a competent patient or designated surrogate may elect to withdraw or withhold mechanical therapies “when burdens exceed benefits.”^{2-4,8,13,14,17} Moreover, deactivation of MCS and euthanasia are distinguished on the grounds that unlike euthanasia, which requires “an active introduction of an intervention designed to result in immediate death, deactivation of [a left ventricular assist device] does not introduce new intervention or surgical injury”^{2(p283)} but rather allows the patient to die from their underlying heart disease.^{2-4,7} Despite ethical and legal permissibility and a distinction from euthanasia, clinicians shoulder a heavy psychological burden when charged with carrying out a patient's request for deactivation. And they struggle to accept death as the abrupt conclusion to what everyone had hoped would be a longer life well lived.^{3,4} The temporal relationship between the act of deactivation and the moment of death causes clinicians to question whether they have crossed an important ethical boundary.

Capacity, the Crux. Unlike many critical care patients, Mr B retained his capacity to participate in decision-making throughout most of his time in the intensive care unit. His capacity, although valued on principle, was a palpable source of contention because it emphasized the inherent subjectivity of the benefit-burden analysis and the distinct clashing of immutable clinical objectives with evolving patient

goals.⁴ Mr B's initial curiosities about end-of-life care and eventual requests to turn off his mechanical supports compelled his care team, at the very least, to respond and, at the extreme, to act.

Although death is not an acceptable outcome for any patient, it is easier to accept for patients whose condition is moribund, which suggests the potential for conscious or unconscious biases that allow clinicians to believe that whenever a patient loses capacity and is unaware of their circumstances, death is the preferred state. Much more difficult to reconcile is a request to deactivate mechanical support from a capacitated patient who is experiencing clinical stability or gradually improving. To allow, with the “flip of a switch,” that voluntary passage of a sentient being over the threshold of death causes considerable moral distress and requires substantial reinforcement from nurses and other support services to accept and uphold these impactful requests.^{1,2,13}

Readiness for Acceptance. Decision-making capacity accompanied by consistent preferences obligates providers to acknowledge and uphold the essential element of patient autonomy, often at the expense of surgical buy-in or decisional authority and without regard for timing or consensus. Surgeons and other members of the care team may struggle to lay aside their decisional authority in favor of upholding patient autonomy because they worry that, despite information sharing, patients may not adequately understand complex mechanical therapies and therefore may ultimately be ill-equipped to decide their fate.^{16,17} That the decision to deactivate MCS is irreversible once acted upon—and that the outcome is certain and final—may also serve to strengthen surgeons' reticence to carry out a patient's request to deactivate MCS.

Nurses, unlike their surgeon and provider counterparts, meet a patient at admission and provide consistent, hands-on care throughout the patient's hospitalization. Although members of the care team pay close attention to medical and mechanical aspects of patient care, nurses tend to the physical and emotional elements of patient care, which enable them to develop meaningful relationships with patients over time.¹ In addition, nurses facilitate and witness patients' adjustment to illness, which can be especially challenging for patients with end-stage heart failure, who have likely

Table 3: Process for Addressing Ethical Concerns About MCS

Anticipate potential ethical concerns.

Listen to the patient and family, helping them articulate their concerns and formulate questions for the care team. Advocate discerningly, choosing method, moment, and issues for most impact.

Be aware of ethical conflicts that may be suggested by the narrative about the patient's care during hand-offs and team.

Proactively identify signs of moral stress as demonstrated by the patient, family, or members of the care team.

Strive to establish consensus among care providers about prognosis, likelihood of survivability (eg, will the patient make it out of the hospital?), and realistic treatment options (including if there are none) to ensure unified messaging.

Advocate for milestone conversations at predictable intervals between the patient and care team to assess progress, share information, reevaluate care goals, and allow for adjustments to the care plan.^{7,11,13}

Engage supplemental services such as palliative care, ethics consultants, or chaplains early in the process.^{1,2,11,14}

Convene interdisciplinary forums to navigate complex decision-making and anticipate critical decision points.^{1,11-13}

Use a systematic process such as E-PAUSE to explore diverse perspectives and ethical challenges.¹⁸

Connect staff who are experiencing moral suffering with supportive resources such as professional mentorship, ethics consultation, or mental health and counseling supports.

Create, implement, and evaluate a standard protocol that outlines a comprehensive, patient-centered process for deactivation of MCS.

Conduct after-action debriefings to identify areas of confusion, conflict, or ineffectiveness in communication, decision-making or team collaboration.

Abbreviation: MCS, mechanical circulatory support.

grown accustomed to the disease's predictably unpredictable pattern of worsening exacerbations followed by suboptimal returns to baseline.^{3,5} Intimately acquainted with bodily deterioration and patients' evolving perceptions of illness, nurses can assist in contextualizing and legitimizing a patient's wishes when care choices seem to defy conventional reason.¹ As a result, nurses may more readily accept a capacitated patient's desire to end mechanical support, even before the likely outcome of death is recognized.

A Way Forward

Caught within a maelstrom of differing perspectives, nurses play a pivotal role in the decision-making process, as they are uniquely poised to absorb and reflect circulating views in order to foster understanding and potentiate consensus surrounding decisions of deactivation.^{7,9} Table 3 outlines practical steps nurses can take to facilitate a systematic and ethically minded approach to complex decision-making. As we explored earlier, nurses can be instrumental in illuminating and proactively addressing the inherent ethical and moral implications that accompany decisions by patients with the capacity to choose to withdraw MCS. We must also acknowledge

that these decisions will never be free of moral angst because at their core are important ethical values that define our profession and the lives of the patients and families we serve. Our best approach may be to anticipate and respond to them before they become a crisis. By doing so, we can preserve our patients' personhood and fulfill our ethical duty to safeguard the integrity of autonomous choice.

Conclusion

Nonetheless, the nurses go to great lengths, at a wearying pace, to preserve whatever life forces remain.

What drives us to push the outer limits of mortality is not a blind pursuit of life or even an irrational avoidance of death, but rather a collective acknowledgment that each patient is a sentient being worthy of bodily integrity and self-determination until their final breath. As described earlier, maintaining space for patient autonomy can be challenging, especially with respect to deactivating MCS in cardiac patients with preserved cognitive function. Despite the rigors of informed decision-making and a steadfast commitment by the surgeon and care team to uphold the implicit care contract, the decision to deactivate or

withdraw mechanical support ultimately rests with the patient.

The lights are low. The only sound is the humming of the right ventricular assist device circuit. I approach the bed and place my hand gently on Mr. B's chest. He lifts his gaze and smiles, his eyes resolute. This will be the final time. We began this journey together several months ago, and now we both accept that we must go our separate ways. We have layered on, and now it's time to peel away. We are letting go. As I turn to go, he says, "I'm sorry. I wish I could be here longer."

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CE Evaluation Instructions

This article has been designated for CE contact hour(s). The evaluation tests your knowledge of the following objectives:

1. Identify steps nurses can take to facilitate an ethically minded approach to decision-making for patients receiving mechanical circulatory support.
2. Reflect on your role as a nurse in assisting care teams to honor a patient's desire to discontinue mechanical therapies.
3. Define the process of informed consent as it pertains to the process of informed decision-making.

Contact hour: **1.0**

Synergy CERP Category: **B**

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