Role of Clinical Ethicists in Making Decisions About Levels of Care in the Intensive Care Unit

Karen Faith, MEd, MSc, RSW
Paula Chidwick, PhD

In the case of Scardoni v Hawryluck, Mrs H was an 81-year-old woman with advanced Alzheimer disease, cardiovascular illness, and septic shock whose family and physician could not agree on goals for care, requiring that a legal decision be made regarding the level of care to be provided. Over time and after much discussion, the multidisciplinary team on the intensive care unit (ICU) reached a consensus that intensive care for Mrs H would not improve her condition. So it was decided that after Mrs H was stepped down to a general medical unit, should an infection or respiratory distress develop, she would not be returned to the ICU. The attending ICU physician informed the family that instead of ICU care, “the hospital would offer her palliative care: painkillers and sedatives to keep her comfortable while her afflictions took their course.” In this particular case, the patient’s family challenged the health care team’s recommendations and insisted that their mother be readmitted to the ICU so that aggressive life-sustaining treatment would continue.

This case, although Canadian, is relevant to ICU settings throughout North America. The purpose of this discussion is not to provide an in-depth ethical analysis, but rather to use the case of Mrs H to characterize one type of health care situation that clinical ethicists could help facilitate. Medical recommendations such as those involved in the care of Mrs H are made to prevent the “revolving door” patient, who according to ICU teams will receive no medical benefit if returned to the ICU. Decisions not to readmit are euphemistically referred to by some ICU staff as the “one-way ticket out of ICU” or “celestial transfer.” Such language shared between colleagues reflects a coping strategy, a “gallows humor,” intended to manage difficult feelings like sadness, anger, grief, sympathy, or moral distress. Cases like that of Mrs H are of

PRIME POINTS

- How decisions are made and communication is handled are essential to ensuring a good outcome.
- Interdisciplinary teams should reach consensus about care plans after considering the values and wishes of patients, standards for care, and the duties of health care professionals.
- Maintain timely, open, and consistent communication with patients and patients’ families.
- Address areas of potential conflict and flag potentially challenging cases early so that proactive strategies can be developed.

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particular concern to critical care nursing. Research has indicated that moral distress, a significant contributing factor to burnout, is encountered by ICU nurses when the care they are providing to a patient is regarded as futile.1

It is not uncommon for hospital-based clinical ethicists to receive a request for consultation when disputes regarding similar recommendations for care arise between substitute decision makers and the ICU treatment team. These cases can lead to moral distress because of commonly held opinions among team members that futile treatment is being provided. Although staff can provide many life-sustaining treatments to such a patient, ethical questions often arise during the patient’s stay in the ICU. What ought to happen when an ICU team decides that a patient should be transferred to a general medical unit to receive comfort measures only, with no readmission to the ICU? Although teams discuss the practical questions about what can be done, the ethical questions about what ought to be done are sometimes not as clear. The following discussion explores how clinical ethicists can provide valuable assistance with the kinds of ethical challenges these situations customarily present. Particular emphasis will be placed on working within a process-driven, interdisciplinary framework that maintains a communication-oriented approach to ethical decision making.

Clinical ethics is a relatively new field, and the role and purpose of clinical ethicists can vary somewhat according to the particular health care setting. For the purpose of this discussion, the authors describe the knowledge, skills, and activities of clinical ethicists through their review of relevant literature as well as their own training and experiences as staff clinical ethicists at 2 acute care settings in Ontario, Canada.

Issues Related to One-Way Transfer

Greater legal clarity or legislative measures to specifically address conflicts that arise over withdrawal or withholding of treatment for terminally ill patients are required, according to at least one legal expert. Current Canadian law, according to this same scholar, leaves doctors, patients and their families in a “grey zone” as to who should have ultimate authority on such decisions.2 The daily reality in most North American ICUs is that this gray zone persists—for better or worse. Although hospitals attempt to provide guidelines for addressing conflicts such as the one involving Mrs H, it is the quality of communication and relationship within the interdisciplinary team and between the treating team and the patient’s family that has a marked influence on decision making.2,2 In most cases similar to this one, consensus about level of care is first achieved by the interdisciplinary team, and a subsequent agreement is reached between the treatment team and the patient’s substitute decision maker and family. However, when agreement cannot be reached because of irreconcilable notions pertaining to what constitutes benefit to the patient and what constitutes harm, the results can be uncertain, stressful, and most unsatisfactory for both the health professionals involved and the patient’s family. This combination of an unfortunate turn of events for the patient, sharing of bad news with family members, and the recommendation for care outside of the ICU is a juncture of decision making at which conflict can occur and ethical challenges are most apparent to members of the interdisciplinary team.3,4

Communication and Conflict Resolution in End-of-Life Issues

Much has been written about the difficulties in communication within the ICU and how this affects patient care. Considerable evidence indicates that communication between the ICU team, patients,
and patients’ families can be inadequate, leading to conflict and a possible long-term effect on the patient’s family. In one study, 46% of families who had a loved one die in the ICU reported conflict over decisions to withdraw or withhold life-support measures. These family members also reported conflict over the manner in which staff communicated with or behaved toward them. The authors of that study cited family members who felt pressured by staff to “hasten their loved one’s death because they placed a burden on valued resources.” The importance of communication between treatment teams and patients and patients’ families cannot be overstated. In addressing the difficulties and deficiencies that have been identified, experts concluded, “communication with caregivers is consistently identified as the most important and least achieved factor in patient/family satisfaction surveys.”

Intensive care is primarily intended to provide maximum benefit to those patients who are likely to recover from their infirmity or trauma. When the interdisciplinary team is not clearly communicating ethical considerations as well as the criteria they are using to determine the effectiveness or success of the treatment plan, patients’ families may develop erroneous expectations that life-sustaining interventions will continue to be offered. At the same time as a loved one is receiving ICU care with a grim prognosis, families are struggling to come to terms with impending loss. Family functioning or experience in coping with loss, unrealistic expectations regarding health outcome, within a societal context of diverse religious or cultural beliefs, can markedly influence families’ decision making about end-of-life care. Such formidable contributing factors further emphasize that effective communication strategies, as well as an appropriate level of sensitivity, ought to be used in ICUs when dealing with patients’ families.

Team communication, in particular communication between disciplines, also has proven problematic in decisions about end-of-life care in the ICU. Critical care nurses have cited difficulties in communication and decision making within interdisciplinary ICU teams. Ferrand et al reported that 75% of the nursing staff who participated believed that “collaboration was inadequate during decision making” despite general agreement that such team collaboration is necessary and desired. In another study, about one-third of the ICU nurses who participated felt “excluded by physicians from patient care decisions and felt their exclusion to be a detriment to patient care.”

In terms of the burdens carried in making decisions about end-of-life care, some evidence suggests that physicians and nurses experience equal burdens. Physicians experience the burdens associated with having to make these decisions, and nurses feel the burden of having to carry out care decisions made by someone else. Given the shared burdens that members of the interdisciplinary team face, as well as the reported difficulties in end-of-life care decision making in the ICU, ensuring effective communication is a key feature of high-quality patient care. The following discussion is intended to demonstrate how clinical ethicists can be supportive of such strategies for effective communication and decision making.

Futility-of-Care Issues

Medical recommendations like those pertaining to the care of patients such as Mrs H are based on best-practice standards of care and are informed by ethical principles like beneficence, nonmaleficence,
and autonomy. Continued life-sustaining support in situations where benefit is in question can be regarded as futile, a concept with inherent ethical challenges. As Weijer et al. 18 point out, the values inherent in medical futility arguments often confuse treatment considered ineffective and treatment that will be effective but will ultimately result in a controversial outcome such as permanent unconsciousness. A team’s decision to not readmit a patient for ICU care can be an attempt to address futility based on controversial outcomes that the team may perceive as causing more harm for the patient than good. Poignantly stated, “if the welfare of the patient is the whole purpose of providing treatment and if that treatment brings needless suffering, then the whole purpose of medicine is defeated.” 19 Although the concept of futility in ICU care is a subject worthy of ethical debate, it will not be the focus of this discussion. Rather, the subject of this discussion is the role of clinical ethicists in helping decision makers address ethical considerations such as futility.

Moral Distress and Moral Residue Issues

The results of inadequate communication, misunderstandings, or disagreements arising from divergent views about what is beneficent and the institutional realities surrounding resource allocation can be seen in the moral distress and subsequent moral residue experienced by both the patient’s family members and the health care staff involved. Moral distress occurs when a person can identify the ethically appropriate course of action, but does not feel able to carry this action forward because of barriers that may include lack of resources, legal limits, institutional obstacles, or imbalances in power, for example. Effects of moral distress on an individual can include feelings of anger, frustration, anxiety, or depression. 20 Moral residue can be encountered when “deeply held beliefs, values and principles” are set aside at the expense of one’s personal sense of integrity. 21 For families of patients, moral residue can manifest in lifelong memories about difficult health care experiences.

The experience of moral distress and moral residue are of particular importance to critical care nursing. Some evidence indicates a relationship between an ICU care nurse’s perception of providing futile care, inadequate communication about the care plan within the interdisciplinary team, and the incidence of moral distress, emotional exhaustion, and burnout. 2,16,22 Cases like that of Mrs H can present these kinds of challenges to nurses providing care at the bedside. The discussion also highlights how clinical ethicists can assist interdisciplinary teams in addressing ethical challenges that can lead to moral distress.

Resource Issues

Finally, the ethical climate within our health care settings is shaped by the organizational values inherent in hospital policies, approaches to handling conflict, allocation of human and material resources, the daily-lived experience of staff providing care, and those to whom care is provided. 2,14 Economic constraints, resource allocation difficulties, and staffing shortages contribute to the moral climate of health settings, the moral distress of staff, and burnout among health care providers. 25,26

In cases such as that of Mrs H, the ethical challenges are not just about treatment requests considered inadvisable but also about scarce resources like ventilator-equipped beds in ICU settings. In the minds of some families, the need for an ICU bed is the primary reason that palliative measures are now being recommended. When conflict surrounds decisions about level of care, it is the bedside ICU nurse who fields the questions, concerns, and emotions expressed by patients’ families.

It is through such challenging decision making, in which no agreement is reached, that the moral climate is regretfully defined for all persons with a stake in the decision. However oppressive these disagreements feel to both health care professionals and patients’ family members, most often the disagreements, ironically, do not result from a lack of good intentions on either side of the debate. Rather, these circumstances reflect the complex ethical challenges that are inherent in contemporary health care settings. Clinical ethicists can be an important resource to health care teams, patients, and patients’ families in addressing these difficult challenges.

Clinical Ethicists As a Resource

Clinical ethicists who provide consultative services may be requested by the ICU team when conflicts such as the one surrounding the planning of Mrs H’s level of care arise. What are the characteristics, skills, and knowledge that make clinical ethicists a useful resource
in helping to address conflict over decisions about level of care for stable but critically ill ICU patients?

Clinical ethicists come from a diverse background of training: clinical and academic experiences that include but are not limited to medicine, nursing, social work, theology, philosophy, and anthropology. Most clinical ethicists have advanced academic degrees and/or training in clinical ethics. Despite this diversity in background, clinical ethicists engage in common functions: consultative services, research, education and the development of policies pertaining to patient care and organizational ethics.27,29

Clinical ethicists are trained to view ethical problems within an interdisciplinary health care environment whose primary commitment should always be to provide the best patient care possible. Patient care and goals for care are best understood through the wishes, beliefs, and values of the patient and the patient’s family. The approach taken by clinical ethicists in providing consultation is to model interdisciplinary collaboration and effective communication with patients and their families, with the objective of enhancing ethical decision making.28,30

In effect, clinical ethicists in cases such as the one involving Mrs H act as facilitators of communication and decision making about goals for care, while directing attention to the ethical considerations underlying such decisions. Generally, clinical ethicists can help clarify differences in the way ethical considerations such as sanctity or quality of life are valued on the basis of religious, personal, or cultural values. Some evidence suggests that ethics consultation generally has been useful in preventing or resolving conflicts, and in reducing the incidence of prolonged controversial treatment.31,32 Current trends in the particular decision is ethically defensible. If so, to whom is it ethically defensible? How ought discussions and conflicts be managed? These questions raise ethical concerns about justice, fairness, and a reasoned approach to decisions of such consequence. Ethical consideration must also be given to the moral climate, how people feel treated, and the concerns and opinions of key persons with a stake in the decision making, with overarching consideration given to trust in the process used to make such important decisions. Therefore

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Clinical ethicists are as concerned with procedural fairness as they are with outcome when assisting with ethically challenging situations in health care settings.

Principal aspects of procedural fairness are as follows: that the process for decision making be as transparent as possible to all involved; that concerns of key persons with a stake in the decision making be considered; that the reasons or rationale behind decisions can be understood and defended; that people responsible for decisions be held accountable; and that in the event disagreement occurs, decisions can be reviewed, taking into account the concerns of those who disagree.28 Process-driven training and education of clinical ethicists have emphasized skills, knowledge, and expertise better suited to provide ethics support in real time as dilemmas and conflict around decisions related to patient care unfold.28

What is particularly important about the approach used by most clinical ethicists is the emphasis placed on fair and just processes for decisions of such importance and consequence in an ICU environment.

**Clinical Ethicists and the Importance of Process**

In cases such as the one involving Mrs H, it is not just what decision ought to be made that is of interest to clinical ethicists, but if and why a
approaches to decision making or to resolving conflict used by clinical ethicists are dependent on using frameworks to guide communication. Such frameworks for communication are not just ethically defensible; they have been shown empirically to be part of good practice standards in ICU settings.\textsuperscript{6,11,34} Lilly et al\textsuperscript{6,11,34} found that using a standardized framework for communication resulted in health care providers seeing decision making as a “process rather than as an event”—an attribute consistent with principles for ethical decision making.

An example of such a framework to guide communication is described by Lautrette et al,\textsuperscript{34} who identify such attributes as timeliness, opportunities for the patient’s family to speak, use of appropriate and sensitive language, and ensuring that the setting is private and comfortable. In addition to these attributes, clinical ethicists would include discussion of the values in conflict and ethical obligations that underscore decision making.

Frameworks for communication appear well supported in the literature anyway, so what makes the involvement of clinical ethicists of added benefit?

Despite advances in implementing communication strategies in many settings, improvement in general is needed in managing communication, enhancing understanding, and meeting needs of ICU patients and their families.\textsuperscript{6,11,34} Furthermore, Sherwin\textsuperscript{36} believes that communication frameworks and hospital policies can be used coercively, to enforce a particular outcome, if those who lead these discussions or who adhere to policies are not reflecting on personal biases, institutional pressures, and ethical considerations.

Clinical ethicists act as facilitators, helping to raise important ethical questions, model effective communication, and model ethical decision making by using teachable moments to heighten the awareness and understanding of the ethical considerations in each case. Within most health care settings, necessary and unavoidable imbalances in power are present between various persons who have a stake in the decision making. Clinical ethicists assist in discussing the values that underlie decisions of such importance, making these transparent to and understood by key involved parties. They model the principles of procedural fairness. Inherently challenging decisions about level of care, as in the case of Mrs H, are often met with challenging feelings and opinions, making fairness and ethical reflection more important than less to involved parties.

Clinical Ethicists and Moral Distress

Clinical ethicists advocate for policies and practices that reduce coercive consequences that can arise when members of the ICU treatment team, patients, or patients’ family members feel overruled or dismissed. In conducting an ethics consultation, the clinical ethicist leads discussions with the interdisciplinary team members about ethical considerations that contribute to moral distress, for example, the conflict in the way benefit and harm associated with a particular therapy or level of care are understood. In most instances, the clinical ethicist must ensure that concerns raised by members of the interdisciplinary team and concerns expressed by patients’ family members are shared and considered. This process is handled in an open and transparent manner. In creating an opportunity through the consultative process for the interdisciplinary team to address concerns, related to both areas of conflict and moral distress, clinical ethicists are also capitalizing on valuable teachable moments in which knowledge about ethics and decision making can be enhanced.

As Kälvemark Sporrong et al\textsuperscript{17,53} concluded, “Ethical competence is a key factor in preventing or reducing moral distress.”

We have found that consultation on an individual case often helps treatment teams identify preventative strategies to reduce or avoid conflict and to engage in more timely discussion about ethics the next time a complex care situation arises. Such measures are necessary in creating a moral climate in which discussion about ethics in daily practice can be supported and thus reducing the effects or incidence of moral distress. The potential exists for all members of the interdisciplinary ICU team, including the most responsible physician, to be so engaged in ethical reflection and decision making on challenging cases. Clinical ethicists model skills of effective communication, ethical reflection, and decision making as well as principles of procedural fairness within the consultative process that they facilitate.

We are not suggesting that effective communication, procedural fairness, ethical reflection, and decision making are deficient whenever clinical ethicists are not involved in
such cases. In reality, complex and ethically challenging cases occur routinely in ICU settings, most often without the involvement of clinical ethicists. What is being proposed is that clinical ethicists should be seen as a valuable resource for addressing challenging cases in the ICU. Better understanding is needed about the role of clinical ethicists and the kinds of assistance they can provide.

Conclusion

In most cases, the ICU team and patient’s family agree on recommendations that comfort measures be provided on a medical intermediate care unit or a palliative care unit for a stable but critically ill patient. However, as in the case of Mrs H, these decisions may be met with considerable emotion from the patient’s family and with differences of opinion about benefit and the appropriate level of care. We think that clinical ethicists can be a valuable resource when challenging cases arise. By providing consultation, clinical ethicists can model effective communication, ethical reflection, and decision making, while following principles of procedural fairness, all of which are key elements to upholding ethics in daily practice and are of particular importance when conflict occurs about level of care in the ICU.

The following are practical considerations for critical care nurses:

- The process used for making decisions and handling communication is an essential part of ensuring a good outcome.
- The interdisciplinary team should reach consensus about care plans after considering the values and wishes of the patients, standards for care, and the duties of health care professionals.
- Interdisciplinary teams are encouraged to maintain timely, open, and consistent communication with patients and patients’ families, with emphasis placed on building trust and maintaining equality and respect for the views of all involved parties.
- Interdisciplinary teams are advised to address areas of potential conflict early and to flag potentially challenging cases early so that proactive strategies can be developed.
- Consultative resources such as chaplains, social workers, and clinical ethicists should be used to uphold ethical ideals for care, support decision making, and reduce conflict and moral distress.
- Decision making should continue to follow ethical principles of inclusiveness, transparency, responsiveness, and accountability.
- The support necessary for staff members and the patient’s family to get through this difficult time and address resultant distress should be provided.
- Opportunities for team review of challenging cases should be provided in order to develop effective preventative strategies.


References


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