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Pregnancy in Serious Illness

It's Not Just Medical Decision Making

Karla Schroeder, DNP, MHA, RN, ANP-BC, NE-BC ❍ Casey Miller, MSN, RN, ANP-BC ❍ Heather Shaw, GNP-BC ❍ Lynn Hutton, LCSW

Pregnancy in the presence of serious illness and treatment can create a moral and ethical struggle. There is little literature to provide an ethical framework for decision making when women become pregnant while receiving aggressive care for any serious illness. The family and care team often have moral distress as they provide support and are integrally involved in decision making. A case study is presented to describe a complicated patient scenario and how all involved can develop emotional, moral, and ethical struggles as care is delivered. In clinical cases where nurses feel that their own ethical and moral frameworks are either in conflict with patient, family, or health care provider decisions, or feel that patient and family wishes conflict with one another or the health care system, emotions and distress rise to the surface. In these situations, nurses can advocate for standard practice and to use an ethical framework for decision making, such as the 4-box method, to help decrease moral and ethical struggles as technology continues to advance in health care.

KEY WORDS

ethical dilemma, moral distress

Through ongoing medical and scientific advancement, people with complex, life-threatening illness, such as heart failure, can live longer and more normal lives. Currently, patients with advanced heart failure have options such as a left ventricular assist device (LVAD), which assists the heart when it cannot provide enough blood flow to support life. Left ventricular assist devices are used as destination therapy or as bridge to heart transplant. These devices can improve quality of life and provide longevity for these individuals.

One complicating factor when using advanced medical technology, such as destination therapy LVADs, is decision making and support should the patient become pregnant. Pregnancy in these patients is discouraged. At present, only 1 documented case of live birth has been recorded for a patient with LVAD.[1] Women with implanted LVAD are encouraged to maintain strict birth control regimens. If conception occurs, they are usually encouraged to terminate immediately because of the teratogenic effects of medications used for heart failure management, the structure and anatomical placement of certain devices, and risks associated with coagulopathies related to pregnancy hormones.

Patients who receive therapy LVAD ideally complete advanced directives prior to implantation. This provides a foundation of the goals of care related to treatment and discontinuation should a life-altering event occur. However, it is unclear if pregnancy is included as a standard part of advanced care planning for women of childbearing age prior to implantation. For women who have an implanted LVAD and then become pregnant, an ethical dilemma arises as they are forced to make difficult decisions weighing their values around pregnancy termination with conflicting values for their own health. In addition, moral distress occurs as teams provide care for women who have become pregnant, death seems imminent, and they are being asked to make incredibly complicated decisions.

In 2005, the North American Nursing Diagnosis Association proposed nursing terminology in efforts to categorize and intervene in complex moral and ethical situations.[2] These terms, ethical dilemma and moral distress, provide the framework for a case involving the pregnancy of a young woman with nonischemic cardiomyopathy maintained with an LVAD for possible bridge to transplant. This case study involves pregnancy, complex decision making, and the use of mechanical circulatory devices. This type of case study was selected because pregnancy in any case of serious illness requires complicated decision making, and there is limited literature regarding procedures to establish goals and wishes prior to initiating treatments if a woman should become pregnant.

Karla Schroeder, DNP, MHA, RN, ANP-BC, NE-BC, is director, Palliative Medicine and Geriatrics, Patient Care Services, Stanford Health Care, California.

Casey Miller, MSN, RN, ANP-BC, is nurse practitioner, Mechanical Circulatory Device and Heart Transplant, Stanford Health Care, California.

Heather Shaw, GNP-BC, is manager, Palliative Care, Stanford Health Care, California.

Lynn Hutton, LCSW, is social worker, Palliative Care, Stanford Health Care, California.

Address correspondence to Karla Schroeder, DNP, MHA, RN, ANP-BC, NE-BC, Palliative Medicine and Geriatrics, Patient Care Services, Stanford Health Care, 300 Pasteur Dr, Stanford, CA 94305 (kschroeder@stanfordhealthcare.org).

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Moral distress can be profound for the patient, family, and team in cases where pregnancy termination is suggested with the intent to protect the life of the patient.[3-5] When an advanced directive does not exist, teams caring for patients can struggle with moral distress as complex medical decisions are made without knowing the patient's wishes.[6]

Summary of the Literature

A PubMed search for the term "ethical dilemma" and "moral distress" in the human species within the last 3 years reveals approximately 358 articles. These articles discuss issues found in allocation of resources during mass casualties,[7] ethics related to transplantation,[8] and the ethical dilemma faced between providing life-sustaining treatment and allowing patients to die a natural death.[9,10] Many other articles involve the moral distress faced by parents and providers in the overlap of pregnancy and childbirth with advanced illness.[3-5] Although these studies all focused on diverse patient groups, common themes arise around the ethical and moral struggles when decision makers have values that conflict with available medical options.[6]

Moral distress is detailed in medical literature as developing when a barrier impedes a decision maker from having the capability to move forward with an ethical or moral action,[6] for example, "when one knows the right thing to do, but institutional constraints make it nearly impossible to peruse the right course of action."[11] There is much research around the complicating factors involved within the development of moral distress among nurses and health care providers.[12,13] Less literature is found around moral distress and lay caregivers as decision makers. However, research reveals more frequent moral distress in the context of futile treatment for nurses, health care providers, and caregivers.[14] Many nurses and other health care providers have expressed moral distress as they care for individuals who they believe are receiving futile treatment. Other investigators are evaluating to quantify and identify the concept of moral distress in health care providers to better understand and intervene in these situations.[15]

In contrast to moral distress, an ethical dilemma arises when the decision maker experiences indecision because available choices or alternatives support conflicting values.[16] Ethical dilemmas occur when situations arise where a choice must be made between 2 options in which resolution of the situation cannot be acceptably resolved with either choice.[17]

There is a notable difference between moral distress and an ethical dilemma. This may be one of the most interesting and challenging aspects of the issues. Ethical dilemmas can cause moral distress, but moral distress does not always mean there is an ethical dilemma. As an example, a patient and family may feel that their decisions and treatment choices are aligned and congruent and therefore have no moral distress. However, the nurse may feel moral distress in this case if he/she feels that the care is not in line with his/her values or perceives that it is not in the patient's best interest, regardless the fact that the patient and/or the patient's surrogate are comfortable with the care being provided. Providers can feel moral distress, even when a patient or family may not. There is notably less literature on ethical dilemmas as opposed to moral distress in health care. Certainly, ethical dilemmas, where nurses, patients, or families perceive that none of the available choices can resolve the issues of tension in care, can be a source of moral distress for all involved.

The Case

The details of this case have been changed significantly to preserve the anonymity of the patient. The patient was a young woman who was implanted with an LVAD because of nonischemic cardiomyopathy from the flu virus several years ago. The patient completed the typical pre-LVAD evaluation, education, consents, and screening; however, she did not have an advanced care plan. The goal for LVAD was destination therapy, which would allow her more time at home with her young children and improve her quality of life. She had strict birth control in place following the medical recommendations. She lived at home with her husband and children and described her overall quality of life as "good."

Three years after implantation, the patient presented to the emergency department at her LVAD center with an acute medical condition, and workup incidentally revealed she was pregnant. The maternal-fetal obstetrics team was consulted, and it was determined she was in her second trimester of pregnancy. Further information revealed that the fetus had been exposed to teratogenic medications since conception including anticoagulation.

Over the next week, many consulting teams became involved with her case including maternal-fetal (maternal-fetal obstetrics team), gynecology, palliative medicine, chaplaincy, ethics, and social work. They outlined the harmful risks to both the patient and her fetus, and consensus was reached throughout all medical teams that she and her fetus were faced with a high risk of mortality if the pregnancy continued. Ultimately, the medical recommendation was made for her to terminate the pregnancy. Interdisciplinary teams worked together to discuss the patient's case and decision making. The patient, family, and providers involved expressed moral distress related to risk versus benefits of treatments. Teams held informal debriefing sessions among themselves initially to help with coping with their own moral distress.

The patient confided in the nurse that she and her husband had deep religious beliefs and felt God had provided them with a special gift. She felt conflict between the medical recommendation to terminate the pregnancy with the goal of preserving her own life and her religious beliefs that her pregnancy was a gift from God. The patient and

her husband had daily visits with the palliative care chaplain. She did not feel that she could make the decision to terminate her pregnancy, even though she understood the grave risk associated with it for both herself and the fetus. The patient also felt constant pressure with numerous providers and staff members entering her room daily, all wanting an answer to what felt, to her, like a private decision.

A few weeks later, however, the patient awakened with a headache and an inability to speak clearly. A computed tomography of her brain revealed a large intracranial hemorrhage with gross midline shift. She was intubated and required ventilator support. She was taken to the critical care unit, and aggressive measures were instituted to save her life and the life of her unborn fetus. Despite these efforts, the stress on her body caused her to spontaneously deliver a nonviable fetus. The nurse who was caring for her at that time felt considerable distress and was supported by her other colleagues as well as the chaplain, palliative care team, and the intensive care social worker. Furthermore, the entire team caring for her required time and space to process and grieve.

The patient required numerous further interventions over the next few months. Because of the inability to be anticoagulated because of the intracranial hemorrhage, she formed a thrombus in her LVAD. There were no surgical options for LVAD exchange because of her recent brain insult, so the medical staff, along with her family, made the decision to discontinue the LVAD and attempt to maintain her cardiac function with inotropic support. Despite all measures and medical interventions, she eventually died in the hospital on full medical support a few months after her initial ED presentation.

Moral and Ethical Decision Making

As this case study illustrates, distress and the subsequent difficulty in decision making have real impact on the health and well-being of patients, their families, and the teams involved in their care. A straightforward methodological framework that can be used to provide structure in complex ethical cases is called the 4-box method. This method brings together the ethical principles along with clinical indications, patient preferences, quality of life, and social, cultural, and economical factors in complex decisions. The 4-box method provides a standard process to facilitate the discussion and resolution of difficult discussions.[18]

In these situations, nurses serve to help treat medical conditions and provide information and support for complex medical decision making. The nurses can provide assessment, treatment, and education, which place them in an ideal role to recognize ethical dilemmas and moral distress. Nurses are critical frontline staff who are integrally involved with decision making and are often affected by moral and ethical issues. During these situations, nurses can develop moral distress as the patient's wishes may conflict with their own inner ideals of right and wrong. Furthermore, moral distress could be related to use of technology, treatments, or lack of planning. Using a structured method such as the 4-box method can provide the simple structure needed as the nurse continues to provide care (Figure).

Ethical Dilemma

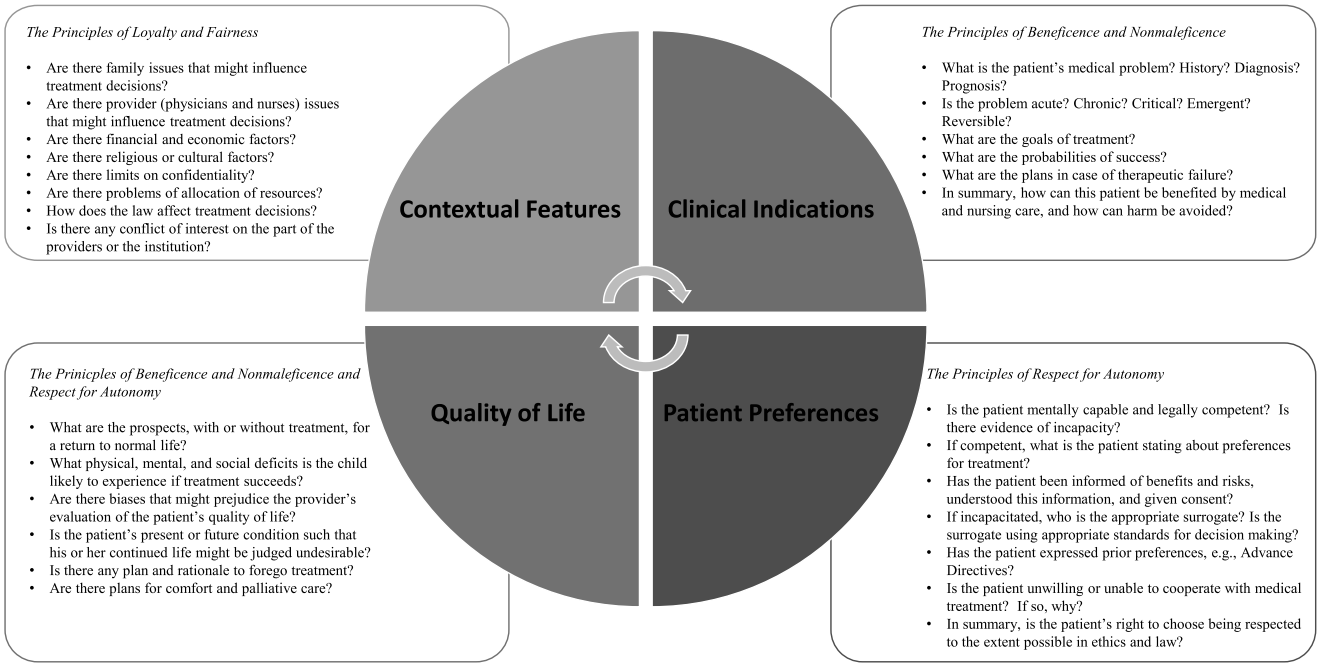
The patient and her husband faced multiple ethical dilemmas over the course of this case study. When the patient was found to be pregnant, she struggled with the difficult decision of whether to preserve her life by terminating the pregnancy or to risk both lives by continuing the pregnancy. Signs a person may be having an ethical dilemma include verbalization of self-conflict, asking questions, requesting help, avoidance, lack of decision making, denial, or expression of guilt.[6] In the case study, the patient ultimately was able to resolve the ethical dilemma for herself by deciding to continue the pregnancy. Complications ensued that brought further moral distress for her husband and the health care teams involved in her care.

Moral Distress

In the case study presented, the patient experienced moral distress when trying to decide between termination of her pregnancy, which would protect her own life, and continuing the pregnancy, which created real risk to both. Likewise, the patient's husband was faced with moral distress many times when acting as a surrogate decision maker for his wife, as he was asked to weigh out the real and grave risks to his wife's life, knowing that she wished to maintain the pregnancy, even at risk to her own health. Signs that a layperson decision maker is having difficulty with moral distress include verbalization, expressed feelings of powerlessness, frustration, anger, feelings of worthlessness, depression, or displaying feelings of moral responsibility.[6]

Morality governs behaviors, which affects others and applies to all rational persons.[19] To act morally, individuals must act in accordance with moral rules, ideas, and virtues. Moral rules prohibit causing harm.[20] This becomes complicated when all decisions, including indecision, create some measure of harm. In this case study, the patient and her husband faced moral distress as they felt that they had to decide to maintain the pregnancy despite the risks. The patient felt that she could not cause harm to her unborn fetus even given the risk to her own health.

The health care providers engaged in this case study confronted moral distress as they guided this family through complex decision making. The patient did not have an advanced directive in place; thus, the providers did not have a foundational understanding of her goals, wishes, or values related to her treatment. Signs that a health care provider may be struggling with moral distress may include anger, self-doubt, diminished confidence, exasperation, cynicism, or frustration.[12]



Jonsen, A., Siegler, M., & Winslade, W. (2015). *Clinical ethics: A practical approach to ethical decisions in clinical medicine,* 8th edition. New York, NY: McGraw-Hill.

FIGURE. Four-box method for ethical decision making in health care.

Nursing Identification of Moral and Ethical Dilemma

The nursing role as frontline staff, who bear much responsibility for assessment and triage of patient condition and needs, means that nurses are in a prime role to both assess and intervene in cases where moral distress and ethical dilemmas arise. This can be used even in cases where it may not be obvious that patients, families, or providers are conflicted and are experiencing distress. Nurses can call attention to the distress and help facilitate the discussion or intervention to address said distress, knowing that few interventions remove the dilemma or distress. As we see further advances in medical technology, nurses need to be able to identify and aid persons experiencing these situations.[6]

As nurses identify moral and ethical distress in patients and families, they can better advocate for support, such as recommending a family meeting and calling on chaplaincy, social work, or ethics consultation for support around decision making. These interventions are well within the scope of nursing practice and highlight the role that nurses can play as a central hub for communication, coordination, and advocacy on the patient care team. Nurses can also assist by simply being a listening presence for these patients, allowing them to openly discuss their worries and fears, along with their happiness and hopes.

Moral distress for the teams caring for patients in similar situations can escalate during the months of intense interactions. Teams can develop a sense of loss and grief related to challenging outcomes, such as those described in this case.[12] Certainly, nurses can also experience moral distress in situations where patients, families, and teams make decisions that are not in alignment with the nurse's personal values.[12,21,22]

In the case study presented here, actions of the nurse that would improve patient care would include the suggestion and involvement in a family meeting to further discuss goals of care and to align the patient goals with the care providers. Furthermore, the nurse can advocate for the team members to have debriefing sessions for the moral distress experienced by the team. In challenging ethical and moral cases, self-care for nurses and others involved are important. Supportive counseling, mindfulness, meditation, and other stress management techniques can be helpful.[21,22]

Outcome and Lessons Learned and Questions Left to Ask

Nurses can be leaders to advocate for standard processes for informed consent, education, and advanced care planning prior to the use of advanced technology as a part of the plan of care.[23] Nurses can identify moral distress experienced by the patient, family, and care team to use the information to develop a care plan. Nurses can provide structured processes for debriefing patients, families, and teams when moral distress is noted.

This case study details multiple areas of ethical dilemmas and moral distress for the patient, her spouse, and the team caring for her. This case study also demonstrates that there are clinical situations in which decision, or lack of decision, can pose harm to the patient. It also shows how issues of moral and ethical distress can be alleviated while opening doors to new or further situations of ethical dilemma and/or moral distress. In this case study, team members had

difficulty providing support in the decision making because of the ethical dilemma and moral distress. Nursing support can be provided through facilitation of information, resource gathering, recommendation of appropriate consult, and supportive counseling.

Consider the following standard practice implementations as health care technology and care continue to advance:

- Standardized process for advanced care planning or preparedness planning, which includes pregnancy for patients of childbearing age who are considering technology as a part of their plan of care.[3-5,23-26]
- Standardized process to mitigate moral distress experienced in cases where complex decision making involves discontinuation of technology and/or termination of pregnancy.[3-5,12,23-25]
- Using a standard process for ethical decision making such as the 4-box method.[18]

CONCLUSION/SUMMARY

Medical and technological advances can be faster paced than the human ability to weigh out the conflicts that can arise from complex decision making. A nurse's ability to identify and name an ethical dilemma and moral distress allows for care planning and advocacy that can support patient decision making. As illustrated by this case study, decisional conflict can result from the uncertainty of choosing one medical plan over another. Through identification of ethical dilemmas and moral distress, nurses can create standard processes that support excellent communication, family meetings, ethics consults, and standard practice and provide direction of the health care team to help support decision making that will ease conflict for patient and families.

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