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On Best Interests

A Case for Clinical Ethics Consultation

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Surrogate health care decision making is often a challenge for everyone involved. In the case of incapacitated patients, family members, nurses, health care providers, and other members of the health care team often grapple with determining the most appropriate clinical course of action. For these difficult patient scenarios, the expertise of clinical ethics consultants is sought to assist with complex health care decision making. Clinical ethics consultation is designed to provide a more objective "outside" opinion and offer advice to the patient, family, and entire care team to support and guide decisions. Nurses are well positioned to initiate assistance from Clinical Ethics Consult Services in support of patient and family advocacy. This article presents a case analysis based on the Stakeholder, Facts, Norms, and Options Framework to analyze the best interest course of action for Mr K., a patient diagnosed with abdominal pain due to end-stage liver cirrhosis and who lacks decisional capacity in regard to his own treatment decision making. The case analysis highlights specific examples of how nurses can provide information, facilitate discussion, and otherwise support patients and families to achieve best interest outcomes.

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THE CASE

Mr K. is a young adult male admitted to the intensive care unit 12 days ago because of hypotension and intractable abdominal pain due to end-stage liver cirrhosis. He has a history of alcohol and other substance abuse, as well as a seizure disorder. He is currently dependent on vasopressors and daily blood transfusions for hemodynamic stability. Mr K. has bleeding esophageal varices and other gastric bleeding. He is obtunded and therefore nonresponsive, but breathing spontaneously. His code status is "full code." He is not married and has 4 children, all under the age of 15 years. On admission to the hospital, he identified his father as his surrogate decision maker, but he has no written advance directive. On the few occasions when his father visited, he would not discuss anything related to his son's code status or end of life, simply saying, "Do everything." His father has not been in to see him recently. However, Mr K.'s mother has been visiting him in the hospital often.

The Clinical Ethics Consult Service (CECS) team visited Mr K. and after an assessment, including a discussion with the health care team, confirmed his current lack of decision-making capacity. Since Mr K.'s father was not visiting frequently and reportedly did not wish to discuss his code status or end of life, the CECS team agreed to contact his mother. Mr K.'s mother was asked about what she knew of his son's current condition. She said that she believed it was his alcoholism that led to his liver failure. She was informed that the health care team believed he was most likely dying and required daily blood transfusions to maintain his life at this point. While she was accepting of his poor prognosis, she was saddened. She mentioned that she only recently learned of his hospitalization and had been in contact with Mr K.'s father via text messages. When asked about Mr K.'s goals, his mother said that he wanted to be home with his kids and provided no additional details.

The following day, Mr K. became further hemodynamically unstable, requiring several blood transfusions during the night. A computed tomography (CT) scan was completed to determine if there was an identifiable source of bleeding. It was agreed beforehand by the health care team that if the bleeding source was identified and an intervention, such as banding, resection, or cautery, was feasible, they would do so. The health care team was scheduled to hold a family meeting with Mr K.'s parents that evening, and the nurse asked the CECS if it would be ethically justified to impose treatment limitations without surrogate permission. Specifically, if the course of bleeding could not be corrected, was the team obligated to continue to provide blood transfusions every day, and were they obligated to attempt resuscitation when the inevitable arrest occurred?

ETHICAL ANALYSIS

This case presents a number of complex ethical issues. Among these are as follows: (1) Given this patient's condition and prognosis, is it ethically justified to limit continued use of blood transfusions? (2) Who should be the decision maker? With regard to the latter, when parents are the surrogates, but they disagree with each other, whom should the health care team consider to be the decision maker? And, once there is clarification about who has authority to make decisions, is the team obligated to follow the wishes of that person regardless of the team's assessment of Mr K.'s best interest? Resolving this dilemma requires understanding of surrogacy in general and the best interest standard specifically as it relates to health care decisions.

SHARED DECISION MAKING

Methods and approaches of health care decision making have swung from being based on paternalism, which is health care provider directed, to autonomy, which is patient driven. More recently, both of these approaches have lost favor, and shared decision making has become a preferred model of decision making. This change occurred as the result of the recognition that health care decisions need to be medically appropriate as well as consistent with the patient's values. The acceptance of this change has been recognized by both western society and its health care community.[1] There is a great deal of literature discussing this method of decision making, ranging from the ideal of shared decision making and the principles involved, to how to accomplish this approach in various clinical settings, including the intensive care unit.[2-4]

In its usual form, shared decision making is a division of labor and responsibility that occurs, at a minimum, between the patient (or their agent or surrogate if the patient lacks decision-making capacity) and a health care provider. The patient's duty in this dyad is to provide his/her values and goals, while the health care provider contributes knowledge and experience.[5] Not to be excluded from this equation is the ever important role of the nurse in this process.[6]

Although this division of labor seems simple, the burdens involved are not always equally shared by those involved, and its meaning can change depending on specific aspects of the patient-provider relationship. For example, a patient hospitalized in an internal medicine unit for 10 days, who has informed the inpatient health care team of his/her goals, might choose to follow the recommended care plan without explicitly being involved in care plan development. In this circumstance, the primary medical care provider along with the nurse (and input from the remainder of the health care team) determines the appropriate treatment plan in context of the patient's goals and preferences. The patient controls whether and how much to work together with the health care provider to make treatment decisions and retains the ability to either reject or acquiesce to the recommendation that the health care provider makes. This collaborative process allows patients, surrogates, and clinicians to reach the most appropriate decisions while considering the best scientific evidence and the patient's values, goals, and preferences.[4]

AN ALTERNATIVE CASE

In an alternate example, the patient who has decision-making capacity might choose to work directly with the current members of the health care team as partners in decision making. The difference between the scenarios depends largely on how involved the patient or the agent (proxy) chooses to be involved in the health care decision-making process. How much a patient wants to be involved can vary depending on various factors such as individual preference, comfort with the care provider, the type of decisions to be made, potential benefits and risks of alternative courses of action, severity of illness, capacity to make decisions, and when decisions need to take place. Clinicians should remain open to tailoring the decision-making process based on patient and surrogate preferences.[4]

ON BEST INTERESTS

The moral authority of surrogate decision makers is not absolute. As Buchanan and Brock[7] state in their seminal publication, the legal standard of substituted judgment first emerged in probate court rulings regarding financial decisions on behalf of persons deemed incompetent of making decisions for themselves. Appreciating the vulnerability of such situations and the speculative nature of substituted judgment, the rulings noted that "a gift may be made to another from an incompetent's estate if the ward would have made this gift if competent, but *only if* the gift is not so large that it would deprive the ward of basic necessities of life, even if the ward, if competent, would have been more generous."[7] In this context, the courts recognized that surrogates are liable to make decisions for others that more likely track the surrogate's interests rather than the ward's interests. In order to protect the ward against such misdeeds, the "basic necessities" limitation was set.

Certainly, in the context of health care surrogate decision making, there are cases in which treatment or use of health care technology is withheld or withdrawn such that the incapacitated patient is not only deprived of the basic necessities of life but is also deprived of life itself. Since such cases exist with clear ethical support—such as for a patient in a permanent vegetative state who has advance directive. This indicates a preference to withhold or withdraw life-sustaining interventions in this situation. Differentiation of the limitations of financial and health care surrogate decision making is needed. A look at the latter suggests that health care surrogate decision makers' moral authority should be limited when the evidence for patient preferences is minimal or nonexistent. For example, imagine if family members at the bedside are asked whether their loved one ever spoke about living permanently on a ventilator and/or with a feeding tube. "We never spoke about such things," they reply. "Who talks about that?" Here, and in similar cases, the limitation of surrogates' moral authority stems from the lack of evidence regarding what the patient would be likely to decide if he/she were considered competent to do so.

THE BEST INTEREST STANDARD

The best interest standard for surrogate health care decision making is designed to facilitate decision making in cases in which there is minimal or nonexistent evidence regarding a patient's preferences toward the decisions at hand. Generally speaking, the best interest standard instructs surrogate health care decision makers to determine a treatment option that generates the most good or benefit for the patient. What this treatment option is will depend on the patient's interests and the degree of value he/she assigns to interests such as avoiding pain or retaining the ability to speak and interact with family.

This standard is not an abstract judgment, such as "An ideal, rational being would choose X." It attempts to take into account what Ronald Dworkin[8] calls "critical" interests. These critical interests are integral to who the person is: critical interests seem tied to commitments and choices that define a person's narrative or are part of a consistent character that is the mark of integrity. For example, a patient who has a long-held preference to avoid life-sustaining treatment in the context of a severely painful terminal illness for which there is inadequate symptom relief available would be representative of a critical interest in the value of quality of life over quantity of life. In this sense, the best interest standard maintains respect for the patient as a person even in the absence of good evidence about what the patient would decide in this particular instance.

Like the basic necessities limitation in financial decision making, the best interest standard is a built-in institutional safeguard to protect patients against surrogate decision makers (as well as health care providers) even if surrogates are accurately reflecting a patient's preferences. Consider a patient who is incapacitated, lacks an advance directive, and is suffering from complications of end-stage dementia. The health care team tells the family that the patient is dying and recommends hospice care. Moreover, and until the patient enrolls in hospice, the health care team notes that it will not perform cardiopulmonary resuscitation (CPR) in the event of a cardiac arrest. Now imagine that the family disagrees with the do-not-resuscitate order. They state that the patient is a fighter and would want to go out with a fight. The important point to note here is that even if the patient prefers CPR, the vulnerability of this patient, the lack of evidence supporting the surrogates' claim, and the degree of harm that would likely occur in the setting of resuscitation override the surrogates' authority. Surrogates cannot place patients in vulnerable situations with a high likelihood of harm, even if the patient would agree. This is one example of how preference-sensitive these decisions can be and stresses the clinicians' fiduciary responsibility to use evidence-based practice and experience in order to implement appropriate treatment and testing.[4]

STAKEHOLDERS, FACTS, NORMS, AND OPTIONS FRAMEWORK

Also known as the "**S**o **F**ar **N**o **O**bjections Framework," the SFNO framework method considers **S**takeholders, **F**acts, **N**orms, and **O**ptions as a basis for analyzing ethical cases. The SFNO method uses root-cause analysis to examine 3 major sources of uncertainty or disagreement regarding decisions when: (1) persons involved have competing interests, (2) uncertainty or disagreement exists about relevant facts, or (3) disagreement or uncertainty exists regarding ethical norms. This approach uses specific probing questions for identifying ethically appropriate solutions.[9] The SFNO approach is applied here to the case of Mr K.

Stakeholders

Mr K. currently lacks capacity to participate in his health care decision making. Although the patient is always the central stakeholder for treatment decision making, and his preferences and values and goals (insofar as known) therefore carry the most weight, Mr K.'s cognitive status hinders the ability to learn of these directly from him. When asked about Mr K.'s goals, his mother said that he wanted to be with his children and provided no additional details. This was an indicator for the CECS team to further explore the life story and personal identity of the patient (and his parents). This could provide information that could help identify patient and family values that shape health care decision making. Respecting the values of all stakeholders requires investing the time and energy needed to fully appreciate and attempt to incorporate these values in treatment planning.

Because Mr K.'s father was not present and was assessed on multiple occasions as unwilling to speak about Mr K.'s prognosis, the CECS reached out to his mother. This was an important step as it allowed the CECS to consult with another person who could potentially make decisions on Mr K.'s behalf. There was also a concern for Mr K.'s dependent children and their well-being. If Mr K.'s father is unavailable to serve as surrogate, and then his mother could fulfill this role; as noted above, both have equal authority as next of kin. His father may have been struggling with coming to terms with his son's morbidity and mortality, might have been uncomfortable with the burden of decision making, or might have had other competing responsibilities that prevented him from being present.

Facts

Explicitly reviewing and considering the facts relevant to the ethical question are an important step. It sometimes reveals differences among the team in what is known or assumed, and it reveals what is not known. For example, there was not an adequate understanding of the reasoning of Mr K.'s father and his adamant insistence on full code status and “doing everything.” The role that Mr K.'s history of seizure disorder and more recent alcohol abuse played in his father's reasoning was not understood. It could be that Mr K.'s father just could not bear to make a decision that might hasten his son's death, leaving Mr K.'s young children without their biological father for the rest of their lives. He also might have simply been overburdened by his other obligations at the time. Similarly, it was not known at the time of this dilemma how involved Mr K.'s mom had been with her son and what her potential role as caregiver for Mr K.'s children would be. While obtaining more complete facts about these issues might not, in themselves, resolve the dilemma, they could be very relevant to reaching a sound ethical response in regard to understanding best interests of the patient and family members.

It also was unclear how much of Mr K.'s current condition had been discussed with him and his family to date at this point, particularly given his father's resistance to having the conversation. Apart from Mr K.'s mother's expression that he would have wanted to be home with his children, there seemed to be little known about his values and belief system.

Equally important to identify are the health care facts. Mr K.'s advanced liver disease in itself carried a very poor prognosis. In the absence of curative interventions, it was likely that his bleeding would continue, and this soon would lead to his death. On the other hand, if a bleeding source could be identified and addressed, although he would still eventually succumb to his liver failure, there would be a chance of survival for weeks to months.

The facts regarding the justification for using CPR in the event of an arrest are relatively well known. In a recent national study conducted by the American Heart Association Get With the Guidelines resuscitation investigators, the average survival to discharge after CPR for adults receiving assisted/mechanical ventilation or vasoactive agents in intensive care units or telemetry units was 18.6%.[10] When considering significant added risk factors for Mr K. (coagulopathy, liver failure, substance abuse, and vasopressor dependence), there is no meaningful likelihood of survival without concomitant anoxic damage, but a very high probability of inflicting further damage.

Norms

The principle of autonomy through consideration of previously known patient wishes and consideration of surrogates' viewpoints to establish best interest for Mr K. are applicable to this case. Also, nonmaleficence and beneficence are key principles establishing the obligation to help and to refrain from causing harm by carrying out actions such as CPR. During CPR, chest compressions can result in broken ribs and possible anoxic injury, further complicating Mr K.'s condition and worsening his already poor prognosis.

According to the American Medical Association's Code of Ethics, if a patient lacks decision-making capacity, the surrogate may decline an intervention or ask for an intervention to be discontinued in keeping with ethical standards for surrogate decision making.[11] This Code of Ethics states that while there may be an emotional difference between not initiating an intervention and discontinuing it, there is no ethical difference between withholding and withdrawing treatment.[11] When an intervention, such as the administration of blood transfusions for Mr K., no longer helps to achieve the patient's desired quality of life or goals for care, it is ethically appropriate for health care providers to withdraw or to withhold it. Consultation with a CECS should be sought whenever the surrogate's decision regarding treatment appears inconsistent with the health care provider's best professional judgment and thus potentially not in the patient's health care interest or violates the patient's previously expressed goals for care.[11] In Mr K.'s case, there was a lack of evidence regarding previously expressed goals for care, but his assigned surrogate decision maker wanted everything done to preserve his life. Both the medical and nursing codes of ethics offer the use of palliative care for symptom management even when cure-directed medical interventions are being withdrawn or withheld.[11,12] Both also support the use of advance directives and early establishment of goals of care for treatments that are in keeping with the known patient values and belief systems.[11,12]

The American Nurses Association Code of Ethics advises nurses to carefully consider decisions regarding resuscitation status and withholding and withdrawal of life-sustaining therapies.[12] Care delivery for an incapacitated patient should be consistent with the patient's previously expressed wishes and known values. It is understood that a surrogate would make decisions for a patient such as Mr K. with these in mind; however, in the absence of an appropriate decision maker, decisions will be made by the health care team that are in the best interests of the patient.[12] The American Academy of Hospice and Palliative Care Medicine and the Hospice and Palliative Nurses Association endorse that withholding and withdrawing nonbeneficial treatment are ethically and morally indistinguishable and are considered acceptable through the course of progressive, life-limiting illness.[13,14] Both the Hospice and Palliative Nurses Association and the American Academy of Hospice and Palliative Care Medicine believe that surrogate decision makers are to be included in this process. However, patient's preferences and best interests, rather than the surrogate's beliefs and wishes alone, should direct the care plan, which always includes relief of suffering.[13,14] It is essential for nurses to be familiar with these position statements and their responsibility for applying them to their clinical practice, particularly as it relates to surrogate health care decision making.[15]

Options

The options for Mr K. include the decision to have the interventional radiology team perform a procedure to attempt to repair the cause of the bleeding or to withhold this intervention. Along with the decision to perform a CT scan of Mr K.'s abdomen, the option to intervene was presented based on the premise that if the results of the CT scan indicated that there was a cause for the bleed that could be repaired, then this intervention would be justified in that it could extend his survival for a short time. Whether to limit transfusions was another decision at hand for Mr K. Part of this decision had to be the intent of the transfusions. Based on the ability to identify and repair the source of the bleed, continuing transfusions could be part of a plan to continue life support in order to allow for some meaningful period of survival. Or, even if no repairable source of bleeding could be identified, transfusions could be continued for a brief time in order to give family more opportunity to be with the patient or simply to have a few more days to evaluate the patient's clinical condition. If the latter were the case, it would be appropriate to determine a preset time for reconsideration of the plan. Briefly postponing final decisions about withdrawing interventions can be useful practice in health care decision making.[11]

The decision whether to perform CPR on Mr K. in the event of a cardiopulmonary arrest was also considered. As noted above, the decision to withhold CPR should rest on assessment of likelihood of harms versus benefits in this particular case, given known probabilities of outcomes of CPR and Mr K.'s specific clinical situation. The Table presents a summary of probing questions and considerations.

CASE DISCUSSION

In further considering Mr K.'s status, his bleeding is in the context of end-stage liver cirrhosis. He complained of pain when awake and requires blood transfusions for hemodynamic support and a radiological procedure that might lead to control of his bleeding if a source can be identified. The ethical question is whether there is an obligation to continue blood transfusions (if the source of the bleed cannot be identified) and whether to attempt resuscitation if Mr K. arrests. Little is known about Mr K.'s values and preferences. According to his mother, he would like to be home with his children. It is possible that if more information could be gathered, it could be determined that Mr K. would appreciate hospice care at home so he may be with his children. This would satisfy both the obligation to keep him comfortable at the end of life (support his well-being) and the obligation to respect his preferences (support his autonomy).

Mr K.'s father—who the patient has identified as his surrogate—is stating, “do everything.” As discussed above, even if Mr K.'s father is accurately reflecting his son's preferences, which is very uncertain, the best interest standard acts as a safeguard against surrogates who place patients at high risk of preventable suffering and harm. Resuscitation for Mr K. would be likely to cause harm with a high probability of little to no benefit. He would likely incur bruising and broken ribs, as well as a possible anoxic injury. All things considered, his condition likely would be worse after the arrest than it is at baseline. In addition, there is ethical justification for withholding blood transfusions if the source of the bleeding cannot be identified. If neither Mr K. nor his surrogate decision maker can provide evidence that there are specific short-term goals that blood transfusions can support and that he can appreciate (eg, an anniversary, birthday, family visit, etc), the transfusions should be considered nonbeneficial. There is therefore ethical support for not only writing a DNAR (do not attempt resuscitation) order but for also discontinuing blood transfusions.

CASE CONCLUSION

Mr K. was taken to the gastroenterology suite, after obtaining permission from his mother for the procedure. Several areas

TABLE Use of SFNO for Ethical Decision Making

Component	Questions to Consider	Possible Responses
Stakeholder	• Who has a stake in the decisions being made? • Should one stakeholder be prioritized over the other(s)?	• Mr K., his parents, and health care team
Facts	• What are the pertinent facts?	• End-stage liver disease with no curative options • No written advance directive • Mr K. identified his father as his decision maker on admission • Father says "do everything" but does not visit often and will not engage in discussions with the health care team • Mother says Mr K. wants to be home with his kids and nothing more • Mr K. requires daily blood transfusions for hemodynamic stability • Full code status
Norms	• What are the relevant ethical principles, norms, and values? • What is the conflict at hand?	• Principles of autonomy, beneficence, and nonmaleficence • Uncertainty exists about whether blood transfusions should continue, Mr K. should be taken to interventional radiology, and if CPR should be performed in the event of cardiopulmonary arrest
Options	• Which actions should be considered? • Is there a compromise?	• Perform the interventional radiology procedure or do not perform • Continue blood transfusions indefinitely, continue for a short time, or discontinue now • Perform CPR or withhold CPR in event of arrest

of bleeding were identified and cauterized. However, upon arrival back to the unit, he experienced cardiopulmonary arrest. Cardiopulmonary resuscitation was withheld, and he died within minutes.

DISCUSSION

Surrogate shared decision making rests on the availability of appropriate surrogates, their willingness to engage in discussion, and clarity on the part of the health care team about decisions (eg, treatment options) that are available for consideration and those that are not. In the case presented, Mr K. is critically ill, and it has been determined that he lacks decision-making capacity. This determination eliminates his ability to determine whether and how much of a partner he wants to be in the shared decision-making process. Mr K. has identified his father as his surrogate, but the question arises of whether his father is an appropriate surrogate decision maker. As described above, the patient's or agent's role in the dyad requires that they identify the patient's values and goals. Mr K.'s father has thus far not been in regular contact with providers and has declined to discuss treatment decisions with the health care team. He has not provided the health care team with information about Mr K.'s values or goals, although he has given the directive to "do everything." Given the father's limited involvement in shared decision making with the health care team, an argument can be made that decision-making authority should pass to Mr K.'s mother. She has been willing to speak with the team about one of Mr K.'s goals and has been present and willing to be involved in decision making.

SUMMARY AND ROLE OF THE NURSE

The significance of the nurse on CECS committees is recognized both nationally and internationally,[16,17] including the importance of their ethics education, training, and practice.[18,19] The current case presented was initiated by the bedside nurse. In this instance, as often true for clinical ethics cases, the issues at hand are not always clear, making the need for ethics consultation warranted. Nurses in various nursing roles request and participate in clinical ethics consultation, with patient advocacy being a top reason for this decision.[20] In these instances, it is imperative for nurses involved to gather necessary information to help provide needed data to the CECS to aid in their organization of facts in order to support the most appropriate decision. The nurse should be present at the team/family meetings to answer questions and clarify misunderstandings and serve as a liaison between the CECS team, other members of the health care team, and the family. As an important member of the health care team, the nurse's perspective is crucial to the discussion with the CECS team in ensuring that information is fully presented. Also essential is the nurses' obligation to help engage the family. For example, in the case presented, Mr K.'s father may have been intimidated by the health care providers. Part of the nurses' role is to help to identify and address family concerns. This could be through clarification of health care jargon and answering and anticipating questions or concerns that the family may have. By doing this, the nurse can help family members to find their voice while building their self-efficacy for surrogate decision making.

Nurses and other health care team members also have an obligation to refrain from causing harm. Nurses often identify cardiopulmonary arrest and initiate CPR. Therefore, it is not uncommon for the nurse to be an assertive member of the health care team in addressing a patient's resuscitation status and ensuring that a DNAR order is initiated when appropriate. For the case at hand, it was important for the nurse to evaluate whether initiating CPR is harmful in advance of the sudden deterioration in Mr K.'s condition. The emotional harm that cases such as Mr K.'s present for the family is significant, and support for the family must be prioritized as well.

The case presented in this article is an example of a common clinical scenario in which the role of the nurse is highlighted as an important part of patient- and family-centered care. The nurse cares not only for the physical but also the psychological well-being of the patient and family. However, the benefits of engaging the unbiased support of the CECS are invaluable to care planning and help to ensure that the patient and family needs are being addressed in the most morally sound way, consistent with ethical standards. These collaborative partnerships help to ensure that the highest quality care is delivered and to ensure the best patient and family outcomes, even in the midst of unexpected or unfortunate patient circumstances such as the one presented in this article.

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