To submit a case that has been reviewed by an ethics committee or to submit papers on related topics in clinical ethics, readers are invited to contact section editor Ruchika Mishra at ruchika.mishra@gmail.com.

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The Case

A Clash between Culture and Care

RUCHIKA MISHRA

KS is a 76-year-old Burmese woman who presented to the hospital with right-sided weakness that had begun two days prior. Although KS had been diagnosed earlier with dementia and had a medical history of stroke, she was living at a nursing home and was able to walk on her own and use her right arm to feed herself. Since her last stroke three years ago, she had also developed aphasia, and her speech has been minimal. During her current hospitalization, KS was found to have a cerebral hemorrhage, but after consultation with neurosurgery, the team determined that no medical interventions were available, and a higher level of care was not required. She also presented with other medical conditions, including severe hypertension, chronic kidney disease, and depression. The patient's blood pressure has remained high. She has now failed a swallow evaluation and is refusing the insertion of a nasogastric feeding tube. The patient has a younger sister who believes, from a cultural perspective, that only the patient should make her medical decisions. As a result, she feels helpless in assisting the team. The medical team has asked for an ethics consultation to direct the patient's care and to guide decisionmaking.

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Commentary: The Reluctant Surrogate

Thomas Foreman

An individual's hesitance or outright refusal to function as a substitute decisionmaker creates a number of challenges for treating teams, as is highlighted by the case of KS. It is not uncommon for individuals who suddenly find themselves in the role of substitute decisionmaker (SDM) to experience feelings of inadequacy or of being overwhelmed. The natural apprehension that comes with realizing, or being informed, that you are now responsible for providing or refusing consent on behalf of a loved one is often exacerbated by the accompanying circumstances. Even though there are movements afoot to encourage and support advance care planning and the inclusion of those who will become SDMs in conversations about values and wishes, there is still much work to be done. Although the case as presented does not provide information regarding what, if any, processes have taken place prior to the current hospital admission with regard to including the patient's sister in discussions about future circumstances, it is clear that the sister feels unprepared to assume the role being thrust upon her. What, then, does a clinical ethics consultation have to offer in such situations? The following discussion highlights three ways in which ethics consultation can be of value to both the treating team and the identified SDM: ethics consultation (1) helps the care team and SDM navigate the regulatory landscape, (2) supports the treating team, and (3) supports the SDM.

The Regulatory Landscape

In every jurisdiction in North America there are legislative regulations that guide and direct the practice of informed consent and substitute decisionmaking. In the absence of a formally identified power of attorney, identifying the legislatively designated SDM(s) can at times be complex. There may well be competing interests and agendas as well as family and interpersonal dynamics to contend with. Although clinical ethics consultation should never replace expert legal advice, ethics consultants are often well versed in the regulatory environment within which they function, especially as it relates to matters of informed consent and substitute decisionmaking. In addition to assisting with the identification of who should function in what role, many regulatory frameworks also provide guidance on what SDMs should take into consideration when providing or not providing consent to proposed treatments or interventions.[1] In the case at hand, there are at least two possible benefits of referencing the relevant regulations. First, although it appears that the younger sister is the appropriate SDM, the care team should explore whether there are any others who have a claim in this regard. This is essential to ensure that the individual providing consent is in fact the legally appropriate person to be doing so. The second benefit is in assisting the SDM in understanding his or her role and function. In the jurisdictions where the regulations specify criteria for substitute decisionmaking, these criteria can be quite helpful for those individuals, as is the case here, who are struggling with feelings of inadequacy or helplessness. Although the regulations do not remove the burdens of decisionmaking from individuals who are struggling, such criteria can be quite valuable in providing a framework within which they can consider the options available to them.

Supporting the Treating Team

As the medical team has asked for ethics support, "to direct the patient's care and to guide decisionmaking," it would seem that the goals of care are yet to be clarified. In addition, the outstanding question regarding substitute decisionmaking needs to be addressed. The clarification and establishment of goals of care that are medically, socially, religiously, and culturally appropriate can be some of the most challenging aspects of the care environment. Care teams often have a reasonable understanding of what the medically indicated goals of care should be, but these can become lost in the quagmire of cultural, religious, and social considerations. Even when these other considerations are well expressed and understood, determining what amount of weight to give them vis-à-vis the medical considerations can be extremely challenging. In our case, the patient's sister is making a cultural claim regarding patient autonomy. The result is that the care team members are challenged with how to respect this claim on the one hand and how to meet their professional ethical obligations to act in the best interests of the patient on the other. In the absence of a willingness or ability on the part of the sister to provide this much-needed contextual information, the team may find itself in a position of being able to consider only medical appropriateness when establishing a proposal for goals of care. It would seem that the team recognizes that this would be insufficient and is thus seeking guidance through ethics consultation. Ethics consultation in this case can help the treating team weigh and prioritize the various contextual and medical realities. This prioritization can then inform the establishment of goals of care that would be both medically appropriate and culturally sensitive.

Supporting the Substitute Decisionmaker

In cases such as this, in which an SDM is struggling with both the responsibility of the role and feelings of inadequacy or helplessness, ethics consultation can serve several functions. The consultant or consultation team can assist the SDM in clarifying his or her role and function. If, as is the case here, the SDM believes that it would be inappropriate for anybody other than the patient to make decisions regarding her care, the ethics consultation can help to clarify the regulatory requirements for decisionmaking for incapable patients. The sister can also be supported in abdicating that responsibility if she feels it is too burdensome. In addition, the consultation can assist her in understanding that, many times, the SDM is simply expressing the voice of the patient at a time when the patient is unable to express his or her own voice. Thus in this case it may well be that the patient is indeed making her own medical decisions but that the vehicle through which this is actualized is the sister. Clarifying this for the sister would thereby relieve some of the anxiety she is experiencing due to the belief that the patient does not have a voice, which would in her mind be culturally inappropriate. Another important benefit of ethics support can be to provide information and support that can be understood to be bias-free and independent. It does not appear in this instance that the sister is suspicions of the motivations of the treating team, but where this is the case, having an independent, neutral individual or group available for support can be invaluable.

Synthesis

Ideally, the consultant or consultation team would meet with each of the parties individually and then facilitate a meeting between the treating team and the sister (as well as including any other family members or supports that the sister wishes to have present). In this case, engaging in a shared decision-making process would be an appropriate approach. This would enable the treating team to make a presentation of what it believes would be most medically appropriate in addition to allowing the sister to express the patient's values, wishes, and any other contextual features she feels are relevant. The consultation can assist all parties in prioritizing any competing values or perspectives with the goal of achieving a common understanding of what goals of care would be most medically appropriate, culturally sensitive, and in the patient's best interests. If, though, at the end of the day, the sister feels unable to fulfill her responsibilities as an SDM, it should be made clear that the treating team will need to secure another party to function in this capacity, be it another family member or through the regulatory process in their jurisdiction.

Note

1. For example, see s. 42 of the Health Care Consent Act, 1996, S.O. 1996, c. 2, Sched. A.

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Commentary: Looking beyond Treatment Refusal

Shilpa Shashidhara

This case illustrates the dilemma that occurs when a patient refuses treatment. When a patient refuses recommended interventions, it can cause much distress among the medical team and family. On the surface, the ethical issue appears to be in regard to treatment refusal. However, when we look deeper, it becomes evident that the question is truly about whether the patient has the ability to make this treatment decision, given her worsening dementia, recent hemorrhage, and depression. In this case, an essential component of an ethics consultation would be to assess this patient's decisionmaking capacity to determine if her refusals are informed. This case has another level of complexity. If the patient does not have decisionmaking capacity, then who would be willing to serve in the role of surrogate decisionmaker? The case raises several ethical questions and thus makes directing a patient's care and decisionmaking challenging.

Respecting the patient's wishes, or respecting autonomy, is one of the fundamental principles of bioethics and medicine. It underlines the important moral concepts of informed consent and the right to refuse medical treatment. However, in order to make informed decisions, the patient must have decisionmaking capacity. When a patient disagrees with medical recommendations, it appears to initiate concerns about whether the patient is decisional. A mere disagreement should not be grounds for questioning capacity. In this case, an ethics consultation would be helpful in addressing the conflict around the patient's refusal of treatment, in guiding medical decisionmaking, and in dealing with the distress that this situation causes for the younger sister as well as the medical team.

Dementia and Decisionmaking

We are told that KS has worsening dementia. A question to consider is how this diagnosis affects this patient's ability to make decisions regarding her care. Patients with dementia are often assumed to lack decisionmaking capacity. Although patients with dementia may have diminished insight into their cognitive and functional deficits, some demented patients may still be able to make reasoned decisions regarding their care. Orientation questions such as the date, month, year, and location are often used to assess capacity. However, in order to appropriately assess decisionmaking capacity, the questions must be more in-depth and complex. Demented patients who have a greater degree of decisionmaking capacity may be able to make a choice about life-sustaining medical treatment and may also be able to choose to forgo certain treatments. Some patients who are unable to make medical decisions may still be able to make decisions regarding how they want to live their life. Given KS's cognitive impairments and minimal speech, assessing her for decisional capacity may be difficult, as she would not be able to easily participate in discussions or respond appropriately to questions. The team can use alternative means to communicate with her, such as repeating information or showing pictures, to assist her in understanding her medical condition and to help her express her preferences. The medical team should make every effort to assess if KS truly lacks decisionmaking capacity due to her dementia.

Depression and Decisionmaking

The case describes KS as being depressed. Is she on medication? If not, should she be? To what degree might this interfere with her decisionmaking? If she has not received a psychiatric consultation, she may benefit from one. It is important to note that not all patients who are depressed or have mental health illness lack the ability to make their own medical decisions. KS's depression may be contributing to her refusal of treatment. A psychiatric consultation may be helpful in assessing if her depressed state could be treated such that she is more agreeable to understanding and receiving required care.

Prognosis from Acute Neurological Insult

We know that the patient has suffered a cerebral hemorrhage, and neurosurgery has provided its opinion that surgical interventions are not indicated at this time. However, a question that needs to be addressed is whether any degree of cognitive impairment this has caused may lessen over time. An indication of the patient's neurological prognosis could help the team understand if the patient has a likelihood of improved cognition over time. If such improvement can indeed be expected, the team would have a chance of having a more meaningful interaction with the patient.

Bases for Refusal

KS's refusal of treatment prompts the request for an ethics consultation, but we are not told on what basis she is in fact refusing certain treatments. Is it because she fears pain/discomfort? Has she had an experience in the past that influences her now? Is she laboring under false understanding or information regarding treatment? Could it be based on cultural identification or religious beliefs? In this case, it is unclear if KS understands her poor overall prognosis and the ramifications of her decision to refuse the nasogastric feeding tube. Many patients find nasogastric feeding tubes to be uncomfortable and ultimately pull out their tube, resulting in, ultimately, being put in restraints. In this case, let's assume that KS has the ability to express her preferences and make simple decisions but that she does not have the ability to make complex decisions regarding her healthcare. Although her refusals may not be informed, her refusals are, nevertheless, important and should be respected and taken into consideration when developing a treatment plan. Even though KS may be compromised, it would not be appropriate to force treatments on her. If the nasogastric tube were placed and KS repeatedly pulled it out, it could cause more harm. Thus, the burden of the treatment would outweigh the benefit.

Values and Beliefs

KS is described as being Burmese. What does this mean? Does it imply ethnicity or something more in terms of values or religious beliefs? If it implies religious beliefs, how would that influence her wishes in her current situation? It is easy to assume that KS and her sister share the same beliefs, but we do not know if that is indeed accurate. Perhaps the sister is voicing her own views and not those of the patient. It would be helpful to explore if the patient's primary care provider had any extended discussions with the patient about her wishes and preferences or who she would want involved in medical decisionmaking if she were unable to make decisions herself. We know that KS has been living in a residential setting. There may be staff members at her facility with whom she may have shared her values at a time when her cognitive function was better than in the current situation.

Surrogate Decisionmaking

If KS is determined to lack decisionmaking capacity and unable to make reasoned medical decisions, she may still be capable of identifying a surrogate decisionmaker. The capacity assessment presents an opportunity to ask KS if there is a person whom she trusts to make healthcare decisions on her behalf. In this case, although the younger sister is unwilling to step up into this role, if the patient identifies her as a decisionmaker, the sister may be more willing to assume this role.

From a cultural perspective, it seems that the sister wants guidance from the patient. It may also be that she struggles in this role because the patient does not have an advance directive, and she is unclear about the patient's wishes about a feeding tube. When family members are expected to make medical decisions, there is a distress and burden that comes with having to take on the role and the decisions they are being faced with. It is even more difficult when family members are unclear about what their loved one's wishes are. The patient's sister should also be made aware that if she is unable or unwilling to function in the role of the surrogate decisionmaker, the team would make decisions for the patient in conjunction with the ethics committee. Many family members do want to be involved in the decisionmaking process, especially when it comes to crucial medical decisions. What they may need, however, is the support and assistance of a professional healthcare provider who can assure them that they are not alone in this process and will have access to required resources from clinicians who have the patient's best interest at heart.

Answering the questions raised previously would be key to this ethics consultation. Clear guidance and recommendations from the patient's medical team and a provider who has an established relationship of trust with the patient can be instrumental in facilitating decisionmaking. It would be helpful to have a family meeting with the patient's medical team, sister, and the ethicist. The physician should clearly explain the medical condition, treatment options, risks, benefits, and possible outcomes. The ethicist can be helpful in providing support and posing questions to help the sister guide the team in making the best decisions for KS. These questions could involve discussing what was important to the patient, what she enjoyed doing, or what she would consider to be a good quality of life. All of these open-ended questions could assist during this challenging process of shared decisionmaking. If the sister were able to answer some of these questions, care decisions for KS could be made using the standard of substituted judgment. She may be able to tell, for instance, that KS loved exploring new cuisines and would go out to dinner once a week with her sister. Even if she were unclear about KS's specific wishes about a feeding tube, she could provide the team with some insight into her interests. One of the important roles of an ethicist besides facilitating discussions is to guide surrogate decisionmakers to make treatment decisions regarding what the patient would want based on his or her wishes and values.

In this case, KS appears to have significantly deteriorated over this hospitalization. However, she may still be able to participate, in some way, in the decisions that need to be made. Her declining medical condition, overall poor prognosis, refusals, and preferences should all be taken into consideration by the medical team and her sister, along with every effort to involve her in the process.

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Commentary: Cultural Issues in Decisionmaking

Ruaim Muaygil

This case presents several fundamental ethical issues. The first issue is the patient's refusal of treatment (a nasogastric tube [NGT] insertion). Second, the patient's refusal of a seemingly beneficial treatment, combined with her medical history, ultimately necessitates an assessment of her decisionmaking capacity. Third, the sister's reluctance to participate in decisionmaking requires a discussion of appropriate surrogate decisionmakers. Finally, the main ethical component to this case is a cultural one, which should be addressed appropriately.

Medical decisionmaking, including the choice to refuse treatment, requires that an individual have sound decisionmaking capacity. Indeed, many well-informed and competent patients reject beneficial treatments for a variety of reasons, including religious beliefs, a desire to lessen suffering, or a desire to seek alternative therapy. For individuals with decisionmaking capacity, a respect for their autonomy, and their choices, is the ethical standard. Yet the knee-jerk reaction of the medical profession whenever faced with such refusal appears to be to question the individual's decisionmaking capacity. In situations in which the declined treatment has a high benefit potential and a low burden, stringent scrutiny of a patient's decisionmaking capacity is certainly warranted. At first glance, this appears to be the case with KS.

However it's not just KS's refusal that requires a capacity assessment, it's her medical history of aphasia and worsening dementia. The first thing on the medical team's agenda should be an assessment of KS's decisionmaking capacity. One useful tool for capacity assessment is the MacArthur Competence Assessment Tool.[1] The tool requires that patients demonstrate certain abilities in order to be found capable of medical decisionmaking. In general, patients must be able to comprehend all the necessary medical information about their condition, communicate a clear medical choice, and coherently explain their reasons and/or values.

In regards to KS, if after the capacity assessment is completed she is found able to make decisions for her own healthcare, then the medical team must respect her autonomy and her choice to refuse the NGT. Her sister's willingness to participate in decisionmaking becomes not only irrelevant but, without KS's explicit permission, inappropriate.

However, what we know of KS's medical history indicates that she suffers from worsening dementia and has been aphasic for years. KS is unlikely to be able to demonstrate an overall understanding of her medical condition, or the consequences of refusing treatment. She is unlikely to be able to articulate a clear choice or participate in a rational discussion with her physician in regard to her reasons for refusing treatment. KS most likely does not have decisionmaking capacity. The medical team must now identify a suitable surrogate decisionmaker to aid in medical decisionmaking.

An appropriate surrogate decisionmaker must be willing and able to take on the responsibility of surrogate decisionmaking, must be available for the medical team, and must be able to understand the relevant medical information regarding the patient's current condition, prognosis, and treatment options. KS's sister acknowledges that her sister's dementia is getting worse and thus appears to show an understanding of KS's general medical condition. She is, however, unwilling to participate in medical decisionmaking due to her cultural belief that only KS can make those decisions for herself.

KS is described in the note as coming from a Burmese culture. There are several ethnic groups within the Burmese culture and multiple religious affiliations, although most practice Buddhism. It is absolutely important for the medical team and the ethics service involved to know more about the Burmese culture, especially in regards to end-of-life care and surrogate decisionmaking. Several resources may be available for the medical team, including online sources, sources within the medical institution itself, or a community house of worship. It is important for the medical team to be cognizant of differences within the same cultural group, and to be aware that just because KS and her sister belong to a certain cultural or religious group, this does not mean they adhere to the values of that group. Therefore, the best source for the medical team would be KS's sister.

A good place to start is to simply have KS's sister help the medical team understand her beliefs and why she chooses not to participate in medical decisionmaking for her sister. Figuring out the exact barriers or circumstances that keep KS's sister from becoming involved may be helpful in determining a way for her to participate in her sister's care that does not go against her beliefs.

Next, the medical team should determine exactly how much KS's sister understands about KS's decisionmaking capacity and long-term medical prognosis. It is imperative for the medical team to address these questions with KS's sister before deciding that she is an unwilling surrogate decisionmaker. It should be made clear to the sister that KS lacks medical decisionmaking capacity, and that her refusal of the NGT is not likely to be based on a well-informed, or a well-considered, thought process. At the same time, the long-term expectation as regards the NGT and potential longer-term artificial nutrition should be discussed; studies have shown no benefit in terms of life prolongation in patients with dementia.[2] A better understanding of the future, as well as of KS's current mental status, may make her sister more comfortable in making decisions for KS. She may see herself as an agent who is communicating her sister's wishes, rather than making decisions for her.

In any ethical case with cultural components, medical professionals must first let go of their own inherent biases, be they a result of their Western background or medical training. They must not pass judgment, no matter how much they may disagree with their patient's or surrogate's decision, and must always keep in mind that their role, first and foremost, is to promote healing and eliminate suffering. This of course does not mean that medical professionals have a blind obligation to follow the cultural preferences of patients and their surrogates; rather, it means that they have a duty to attempt to accommodate them as much as possible.

In regards to KS and her sister, the medical team cannot, of course, force the sister to make decisions for KS. If the sister remains unwilling, and no other appropriate surrogate decision-maker is identified, KS then becomes an unrepresented patient. In that case, a legal petition must be filed for a legal capacity declaration. A conservator, willing and able to make medical decisions on her behalf, will be appointed for her by a court of law.

Notes

1. Appelbaum P. Assessment of patients' competence to consent to treatment. *New England Journal of Medicine* 2007;357(18):1834–40.
2. Murphy L, Lipman T. Percutaneous endoscopic gastrostomy does not prolong survival in patients with dementia. *Archives of Internal Medicine* 2003;163:1351–3.

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What Actually Happened

The medical team found the patient to lack medical decisionmaking capacity. However, the team felt that the patient was still able to respond appropriately to some situations. KS had displayed a consistent refusal of all medical treatments that made her uncomfortable or caused pain. During her sister's visits, the patient would be much more receptive to eating. A meeting was planned with the patient's sister in which the ethicist explained that the patient was not able to make her own decisions. The patient's sister agreed that she would honor the patient's wishes but would let the team make any decisions outside of what she knew about the patient's preferences. The patient's sister agreed and was willing to be at the patient's bedside as much as she could to encourage her eating. If the patient's condition worsened, it was discussed that the team honor the patient's wishes and not force a feeding tube on her. The patient's code status was also addressed, and KS's sister felt comfortable in communicating to the team that the patient would not want to be resuscitated if medical treatments would not be able to improve her current quality of life. A natural passing away would be most amenable to the patient. The patient was discharged to her nursing home with a physician order for life-sustaining treatment (POLST) form signed by the sister documenting a do-not-resuscitate code status with comfort-focused treatments.