Poststroke Communication

An illustrative case with tips for difficult honest empathetic preference-based conversations with surrogate decision-makers.

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Severe stroke represents a sudden decline in functional status and lifestyle for affected individuals, along with a high risk of immediate and longer-term mortality. Family members are often required to adjust expectations, grieve the loss of former relationships, learn to become caregivers, and engage in early discussions around medical decision-making with little or no preparation (Case: Mrs. J Has a Severe Stroke). Although prognosis is often uncertain and outcomes may not be clear for months or years, decisions around life-sustaining treatment (LST) (eg, intubation, decompressive surgery, feeding tubes, and tracheostomies) must be made in the first hours to weeks poststroke. This mismatch presents a challenge to those asked to act as surrogate decision-makers for their now-incapacitated loved ones, whose treatment preferences may or may not be known. Serial conversations are often required to allow surrogates to process serious news before being asked to make difficult next-step decisions.

Case: Mrs. J Has a Severe Stroke

Mrs. J, age 81, with known vascular risk factors, presented this morning with acute neurologic deficits consistent with right middle cerebral artery (MCA) syndrome, with a National Institutes of Health Stroke Scale (NIHSS) score of 16. She was treated with intravenous recombinant tissue plasminogen activator followed by endovascular thrombectomy for proximal right MCA occlusion with excellent recanalization. Hours later, she became less responsive with labored breathing, and repeat head imaging is now consistent with malignant infarction with cerebral edema and impending signs of herniation. Her neurologist, Dr. X, recognizes that urgent decisions must now be made regarding the use of LST. Mrs. J has not previously designated a durable health care power of attorney. Based on the laws in her state, Dr. X identifies her husband as the appropriate surrogate decision-maker and arranges to meet with him in a private conference room.

Neurologists should not hesitate to involve interdisciplinary team members, including chaplains and social workers to support families, and should also consult specialty palliative care providers when appropriate. Still, the treating neurologist will have the most knowledge of the patient's prognosis and the risks and benefits of interventions. Therefore, neurologists must be prepared to use primary palliative care skills to lead these discussions.[1] We aim to provide neurologists with communication tools to guide these conversations with confidence and empathy, enhancing the therapeutic relationship and improving the experience of surrogates in challenging times.

Exploring Values With Preference-Based Discussions

Shared decision-making is a collaborative process between patients and clinicians that involves creating individualized care plans that integrate clinical expertise, best evidence, and patients' values and preferences.[2] By definition, this process involves eliciting what is important to the patient (Box). Before using the term "meaningful neurologic recovery," it is imperative to understand how the patient defines meaningful. For example, a librarian who needed a wheelchair to function

BOX: Eliciting Preferences

What was _____ like before this stroke?
What did (s)he do for a living? What were his/her hobbies?
What role does _____ play in your family and community?
What brings _____ joy and meaning?
What aspects of life have been most important to _____?
What abilities are so critical to _____'s life that (s)he couldn't imagine living without them?[3]
How much would _____ be willing to go through for the possibility of more time?[3]
Has _____ ever been very sick before? How did (s)he react?
If _____ became sicker than (s)he is today, what might (s)he worry about?
If _____was at the end of his/her life, what would be most important to him/her?
If _____ was sitting here with us today, what would (s)he say?
What else might _____ want me to know about him/her?

prestroke may be more accepting of residual limb weakness than would be a marathoner. Understanding the patient's minimal acceptable outcome (MAO) is of great value to the treating team before considering aggressive interventions.

Because strokes frequently leave patients unable to make complex decisions, preference-based discussions are often held with surrogates. Because stroke is acute and unexpected, patients often have not had explicit discussions with surrogates about their wishes. Advance care planning documents can shed light on general preferences for medical care but are often ambiguous and rarely helpful for specific situations. A clinician's role is to guide surrogates to provide deeper insight into the patient's values. This can be done with exploratory questions about the patient's daily life, role in the family and community, past experiences with illness and disability, and importance placed on quality vs quantity of life.[3] Together, the clinician and surrogate can then extrapolate preferences, apply them to the specific situation, and reach decisions (Case: Getting to Know Mrs. J and Box). Although multiple professional societies emphasize a shared decision-making model as best practice, how families look to physicians for help with decision making varies with personal and cultural factors.[4]

It is critical that surrogates understand they should base decisions on their loved one's preferences and values (substituted judgment), rather than their own.[5] This may have an added benefit of alleviating surrogate's guilt by emphasizing they are honoring their loved one's wishes. Gentle reminders to use substituted judgment may be needed throughout the process, with encouragement that there is no "wrong choice" as long as the patient's preferences are respected.

Discussing Prognostic Uncertainty

Prognostic uncertainty can create discomfort that may lead providers to avoid future-oriented conversations; however evidence suggests surrogate decision-makers appreciate acknowledgment of prognostic uncertainty, and often want prognostic estimates despite uncertainty.[6] Surrogates also need this information to make acute decisions and develop a realistic picture of what life may look like if LST is pursued. Acknowledging the inherent anxiety in decision making when prognosis is uncertain, neurologists should assure surrogates they will partner with and support them in a shared decision-making process.[7] After eliciting apatient's MAO, it is useful to give a prognostic estimate in a "best, worst, and most likely case" framework (Table),[7] which allows families to make decisions accounting for a range of possible functional outcomes, helping them "hope for the best and prepare for the worst" concretely and realistically. It is crucial to include outcomes defined as meaningful to the patient (eg, ability to live at home or perform self-care) in addition to more concrete neurologic outcomes (eg, recovery of motor function in a limb). After describing possible outcomes, the neurologist can describe LST and time needed for maximum functional recovery. After discussing benefits and burdens of available treatments, neurologists can help surrogates compare anticipated outcomes to the patient's MAO and ask, "Would your loved one be willing to undergo these treatments for this amount of time for a chance at the most likely outcome described?" Knowing the patient's MAO allows a neurologist to recommend whether available treatments are likely to meet patient-specific goals (Case: Framing Uncertainty).

If a surrogate believes their loved one would accept some projected outcomes but not others, or if patient preferences or anticipated outcomes are particularly unclear, a time-limited trial (TLT) of LST may be appropriate. At the end of the trial, doctors and surrogates can assess the patient's progress toward the MAO, and LST may be continued or de-escalated at that time, depending on whether adequate progress is

Case: Getting to Know Mrs. J

Dr. X introduces herself and says, "I am sorry we are meeting under these circumstances. What is your understanding of your wife's condition?" Mr. J replies "She had a large stroke, but they were able to remove the clot." Dr. X validates his accurate understanding and adds, "Unfortunately, despite the clot being removed, the stroke caused significant brain swelling resulting in severe neurologic impairments. Mrs. J is not able to move or feel the left side of her body, communicate clearly, nor recognize faces. I am worried there is a possibility she could die from this."

Dr. X stays silent as tears well in Mr. J's eyes. He answers, "Is there anything you can do to save her? She is my best friend. Without her, I will be lost!" Dr. X continues empathically, "I can't even imagine how scary this is. Before we go into details of possible treatments, it would be helpful to hear about what your wife was like before her stroke. What brings her joy and meaning?"

Mr. J shares, "I wouldn't be here if it wasn't for her. She drives me to my dialysis appointments, cooks all my meals, and keeps our house in order. I don't know how she did it all! She was starting to slow down lately, but never wanted to ask our kids for help. She didn't want to be a burden. She always cared for everyone else." Dr. X replies, "So she really valued her independence and sought meaning in caring for others. Are there certain abilities that were so critical to her she couldn't imagine living without them?" Mr. J replied, "Well if she couldn't care for herself, I don't think she could handle it. When she had her hip replaced a few years ago, she couldn't stand being looked after in the nursing home. She told me she would rather die than go back there!" Dr. X replies, "It sounds like she thought being dependent on others was worse than death." The husband replies, "Exactly. If she gets through this, you don't think she will require a nursing home, do you?"

TABLE. FRAMING PROGNOSIS

Possibilities	Example wording
Best case	If she receives maximal medical therapy, I am hopeful that over several months, she may regain the ability to___.
Worst case	It is possible that, despite aggressive treatment, she may not recover or may worsen, resulting in _____.
Most likely case	Although it is impossible to know for sure, I anticipate that her most likely outcome is somewhere in between and may include _____.
Additional considerations	In order to achieve the best possible outcome, she would need intensive interventions including _____, and would likely require this level of care for a period of _____. Complications could happen that would make a good outcome less likely, such as _. If these occurred, we would need to have another conversation about what outcomes were still possible.
Non-abandonment	Making decisions can be challenging when we do not know what may happen. I want to assure you that I will be here for you, and that we will find the way forward together.

Case: Framing Uncertainty

Dr. X says, "It is impossible to predict the exact degree of recovery she will have. However, I can share a range of possibilities. In the best-case scenario, she may gradually regain some strength of her left side so she can walk short distances with assistance and participate to some degree in her own care. In the worst case, the swelling in her brain could increase further over the next hours to days and result in death, despite all interventions. The most likely scenario if all interventions are pursued would involve 24-hour nursing care at home or in a facility because of persistent weakness and limited ability to engage in her own care. To give her time to reach her best possible outcome, she would need invasive interventions including surgery to remove her skull cap, insertion of breathing and feeding tubes, and months in a nursing facility with intensive physical therapy.""

After pausing to allow Mr. J time to process, Dr. X continues, "Unfortunately, I don't anticipate your wife will be able to avoid a nursing facility or be independent for her care, even in the best case. Aggressive treatments are unlikely to result in an acceptable quality of life for her, based on what she valued."

Mr. J replies, "So then what do you recommend, doc?"

being made.[10] A TLT may also help surrogates better grasp benefits vs burdens of treatments and provide time for multiple surrogates to reach consensus if needed.[8] It is important to help surrogates identify measurable outcomes and an appropriate time period (often 3-6 months poststroke) for the TLT. Providers should discuss potential stroke complications (eg, sepsis, recurrent stroke, cardiac arrest) that may significantly affect prognostication and require an earlier reassessment of the appropriateness of continued LST. It should be noted that the majority of the TLT will likely occur after hospital discharge, and follow-up with a trusted physician will be instrumental to guide further decisions and facilitate de-escalation if desired.

Making a Recommendation

At the forefront of the modern Western patient-doctor relationship and patient-centered care is respect for patient autonomy. Consequently, clinicians sometimes misinterpret their role in the decision-making process as limited to providing medical information only, with a duty to remain neutral and withhold recommendations.[9] This can leave patients and surrogates carrying the decision-making burden alone, without the medical expertise to fathom the implications of their decisions. This emotional burden has a negative long-term impact on at least one-third of surrogates.[10]

Once patient values and preferences are defined, the clinician's responsibility is to discuss whether considered interventions will meet their MAO, based on clinical expertise and best evidence, and then make a recommendation (Case: Dr. X Makes a Recommendation and Case: Letting Go). Any recommendation, from aggressive medical care to comfort-focused care, may be appropriate depending on the patient's known values. Clinicians are not required to offer or provide interventions that may not yield benefit or could cause disproportionate harm, even if requested by surrogates. Clinicians need to acknowledge their own biases and try to prevent these from unduly influencing recommendations. Ideally, a shared decision-making process will result in consensus among providers and surrogates, lifting a portion of the burden from surrogates.

Case: Dr. X Makes a Recommendation

In answer to Mr. J's request for a recommendation, Dr. X says, "I recommend an alternative approach of shifting the focus of her care away from extending her life. Instead, I recommend we focus on aggressively treating symptoms that might be causing her discomfort, and allow her to reach the end of her life in dignity and peace." Mr. J asks for time to think things over. Dr. X says, "I know this is a hard decision. We do need to move quickly because things are changing fast for her. I will return in 1 hour to see how you are thinking about this."

Case: Letting Go

When Dr. X returns, Mr. J shares that he has talked it over with his kids who agree Mrs. J would not want surgeries or other invasive treatments that would only prolong suffering. "If she couldn't return home to an independent state, she would not want to be kept alive. As much as I will miss her, we have to let her go." Dr. X remarks, "I admire your commitment to honoring her wishes. Because we will be focusing on maximizing her comfort, we will not perform uncomfortable procedures aimed entirely at extending her life. This includes CPR when her heart stops and inserting a breathing tube if her breathing becomes labored." Mr. J replies, "I understand. Thank you."

Conclusion

Clinicians can ease decision-making burden of surrogates by eliciting the patient's MAO, providing a prognostic estimate using the above proposed framework, and making a recommendation based on the likelihood that considered interventions will meet the patient's MAO and goals. This nuanced process is often best as a series of conversations. Interactions and outcomes will be improved when surrogates and physicians keep a patient's personhood and values at the center of discussions. Clinicians may even find this shared, personalized approach more meaningful and rewarding. ■

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