Ethical Approach to Surrogate Consent for Hemicraniectomy in Older Patients With Extensive Middle Cerebral Artery Stroke

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See related article, p 2830.

The recently published Decompressive Surgery for the Treatment of Malignant Infarction of the Middle Cerebral Artery (DESTINY) II trial has reignited the controversy over performing hemicraniectomy in the elderly population, highlighting the question of how preference-based medicine should be applied to patients with severe stroke. The trial concluded that hemicraniectomy increased survival without severe disability. The surgically treated group had better scores across multiple outcome measures including the percentage with no to moderately severe disability (score of 0-4 on the modified Rankin scale) and mean scores on scales assessing stroke severity (the National Institutes of Health Stroke Scale [NIHSS]), activities of daily living (Barthel Index), quality of life (the Short Form-36 Health Survey scales), depression (Hamilton Depression Rating Scale), and self-assessment of overall quality of life (EuroQOL scales). However, the majority of survivors required assistance with most bodily needs. No patients in the surgical group had zero or slight disability, one third were dead at 6 months, and nearly one third were bedridden, incontinent, and requiring constant nursing care and attention.

The high degree of outcome disability after hemicraniectomy in older patients raises vexing ethical issues of communication with and consent by surrogate family members. Before this study, one third of hemicraniectomy procedures performed for ischemic stroke were done in patients >65 years of age, and the overall rate has increased over the past decade. As the population ages and stroke care becomes more aggressive and better organized regionally, the number of eligible patients will likely continue to rise. Here, we offer an ethical framework for consent for hemicraniectomy that integrates outcome data with patients’ values and preferences.

The ethical foundation of medical decision making is informed consent. Clinicians require the informed consent of incapacitated patients except in emergency situations where standard accepted therapy may be given under a doctrine of presumed consent. Because patients with stroke in whom hemicraniectomy is being considered are nearly always incapacitated by stupor, coma, or aphasia, a surrogate decision maker must provide consent.

The elements of informed consent that make surrogate decision making valid are that the surrogate must be given adequate information, namely that which a reasonable person needs to make a medical decision. Reasonable people need to know their diagnosis, prognosis, and choices of therapy with a general description of the risks and benefits of each option. This information should be communicated objectively without exaggeration or influenced by a framing effect and presented compassionately with realistic expectations. Physicians cannot coerce the surrogate whose decision must be made freely.

Surrogate decision making in hemicraniectomy has several obvious limitations. Clinicians may not fully understand the hemicraniectomy outcome data or apply them correctly to an individual patient. Physicians’ technical explanations of hemicraniectomy and its outcomes may not be understandable by unsophisticated surrogates. Physicians may subconsciously insert their own biases of the values of outcomes in framing their discussion. And surrogates may feel coerced by the urgency of the decision and the existential quandary of choosing between death and severe disability. Under these circumstances, surrogates often rely on the physician’s opinion of what should be done. Medical ethics permits physicians to beneficently and gently guide surrogates to make the best decision. This appropriate counseling role of physicians to use their experience, knowledge, and judgment becomes objectionable as paternalism only if the physician disenfranchises the surrogate by unjustifiably overruling his decision.

Physicians should instruct surrogates to follow established ethical and legal standards of decision making. The best decision usually is the one which the patient would have made if the patient were able to decide because this standard respects the patient’s autonomy. The physician should first ask the surrogate if the patient has written advance directives or has spoken about his preferences in this particular circumstance. If so, these expressed wishes should be followed. This standard is rarely usable because most patients cannot have anticipated a particular medical event to provide specific guidance for it.
Next, the physician should ask the surrogate to try to reproduce the decision the patient would have made—based on the surrogate’s understanding of the patient’s values and preferences for various treatments—to fulfill the standard of substituted judgment. Although this standard has been shown to be accurate in only ≈2/3 of cases, it is usually a better option than the alternatives. Only if the patient’s preferences and values are unknown should the physician ask the surrogate to balance the benefits of hemicraniectomy against its burdens to thereby reach a best interests judgment.

This idealized ethical decision-making framework encounters problems when applied to obtaining surrogate consent for hemicraniectomy. Surrogates may not know if the patient would prefer a life of significant disability to an earlier death and be fearful of making the wrong decision in an emergency situation in which there is no time for thoughtful reflection or to discuss the decision with other family members. Physicians may inappropriately insert their biases about their preference for death versus disability by the words they use and how they frame the discussion. And there are no guidelines that govern when physicians should not even offer hemicraniectomy as a treatment option if, for example, the patient is >80 years old and has preexisting dementia, a poor quality of life, or significant medical comorbidities. It is ethically acceptable for neurologists to select patients for whom hemicraniectomy may be offered to surrogates by eliminating those for whom it is not a reasonable treatment option, but this preselection must be evidence based and therefore medically justifiable.

Experienced neurologists know that the context in which urgent hemicraniectomy becomes a treatment option is a perfect storm for difficult decision making. Stroke catches people unprepared and often away from home without family nearby, there are time constraints limiting the benefit to the procedure (usually recommended within 48 hours of onset), and the prognosis is uncertain. The patient is unable to participate in the discussion, advance directives usually are vague and ambiguous to apply to this specific situation, the lawful surrogate decision maker is often unavailable, and the informal family surrogates often cannot be assembled. In this setting, the family decision maker feels forced to make a rapid and draconian choice between death and severe disability. To make the decision process even more challenging, it may be difficult to apply the DESTINY II data. The patient under consideration for hemicraniectomy may not be as good a surgical candidate because those enrolled in the DESTINY II trial whose median age was 70 years and excluded patients preexisting disabilities. Finally, families may arrive from another hospital with the expectation that hemicraniectomy will be performed once a patient has been transferred to a specialized facility, which adds another complicating factor.

The DESTINY II trial challenges us to reflect on the biases about disability that both surrogates and clinicians bring to this discussion and how these subjective factors could lead to inappropriate decision making. One common bias is the focusing illusion in which people disproportionately emphasize certain factors such as having a gastrostomy tube, whereas ignoring other arguably more important factors that may make life satisfying. Another common bias is the failure to appreciate the disability paradox in which a disabled patient reports a higher quality of life than do healthy people who imagine themselves in similar circumstances. Interestingly, in the DESTINY-S study, the degree of bias among clinicians varied by country. Poignant accounts from survivors of severe stroke and hemicraniectomy challenge our assumptions about what kind of life stroke survivors find meaningful and emphasize the importance of social support and long-term postoperative rehabilitation therapies to assure quality outcomes.

Applying the principles of palliative care and medical ethics, the field of neurocritical care has yielded a road map that helps identify and limit biases, enhances refinement in how we prognosticate and view patient outcomes, and highlights a better way to conduct a fruitful discussion about life-sustaining therapies including hemicraniectomy. This work calls us to be more mindful of our biases, as well as surrogates’ biases, and the power specific words can exert on surrogate decision makers and influence their decisions (eg, withdrawal of care and nursing home). As we develop this road map, we should consider how new technologies can assist or hinder appropriate decision making. For example, educational tools for patients and surrogates could be developed to facilitate more appropriate decision making in hemicraniectomy. Examples include educational tools such as those used in understanding thrombolysis for ischemic stroke, including diagrams and flow charts describing hemicraniectomy and the issues in prognosticating and considering different outcomes. Telemedicine consultations by stroke and neurocritical care experts can inject expertise and authority that may be helpful to both surrogates and clinicians. Simulation-based training can help clinicians learn critical communications skills and strategies to improve dialogue with surrogates and family members.

Neurologists offering hemicraniectomy can perfect the practice of preference-based medicine by studying and learning these principles. Clinicians should be simultaneously guided by their patients’ values and preferences for treatment as expressed by their surrogates while mindful of the powerful influence on surrogate decision making that they exert by their framing of decision making. The art of medicine is to blend skillfully the objective presentation of factual hemicraniectomy outcome data with a rational and unbiased treatment recommendation that allows the neurologist to work compassionately with the surrogate to understand the patient’s treatment preference to reach the best decision for the patient.

Disclosures

None.

References


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