Response to Letter Regarding Article, “Outcome Following Decompressive Hemicraniectomy for Malignant Cerebral Infarction: Ethical Considerations”

We read with interest the letter by Woodworth and Simard, and we thank them for the interest in our work. They have asked the question what should guide us when making these ethically challenging decisions, and in many respects, we have produced more questions than answers when we have explored some of the issues on consent.

To try and determine opinion among competent individuals on survival with severe disability, we have conducted studies among healthcare workers in which they were presented with the outcome data as shown in Figure 2 of our article. They have asked whether they would opt for decompressive surgery in 3 clinical scenarios in which they were the injured people with the predicted risk of unfavorable outcome of 70% to 80%, 80% to 90%, or 90% to 100%. The implication, which was clearly stated, was whether they would provide consent in these circumstances based on what they perceived to be the most likely outcome.

Overall, the majority of participants considered survival with severe disability as unacceptable irrespective of age, religion, or clinical background, and as the injury severity increased, fewer participants indicated that they would provide consent based on the increasing probability of survival with severe disability. It could be argued that this hypothetical situation is not representative of the real-life tension that occurs in the context of acute neurotrauma but, as Woodward and Simard note, it could equally be argued that in the real-life acute setting hasty decisions may be made under the pressure of limited time and emotional competency. Thus, the responses of the participants in these studies may better reflect how many people genuinely feel. We recently completed a similar study investigating the issue of consent for decompressive hemicraniectomy after malignant middle cerebral artery infarction with similar results. We can infer that most reasonable persons, capable of making informed decisions, would not accept an intervention that results in survival with severe disability and necessitating long-term care. Indeed, these circumstances may require clinicians to take more responsibility for the decision-making process to ease the emotional burden on grieving families, rather than offering them the false hope of a miraculous recovery.

We would acknowledge that people gain considerable social utility by taking all measures to protect those most in need, and the Rule of Rescue describes the powerful human proclivity to rescue a single identified endangered life, regardless of cost or risk. However, the difficulty comes when the rescue system is seen as a juggernaut that is insensitive to the way we actually value our lives. A compromise has to be reached to determine at what point either the likely outcome would be unacceptable to the person concerned or the social utility gained comes at unconscionable cost. It is clearly neither a good use of resources nor respectful to the autonomy of patients to condemn them to a future they would not have chosen for themselves at great cost to other having individuals who must compete for the available healthcare resources.

There is little doubt that some survivors of decompressive surgery retrospectively express positive feelings, perhaps because of adaptation or recalibration; however, this cannot deserve the same weight as the wishes of informed individuals who are contemplating various future possibilities while in sound mind to deliberate about their values. The use of aggressive surgery to satisfy a demand of fight to the last breath is in the best interests neither of the individuals nor of society. Therefore, clinicians and the community must consider how to deliver healthcare that is both humane and most beneficial to all concerned.

Disclosures

None.

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