INVITED COMMENTARY

Doc, will my relative wake up and be normal?

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One of the most difficult skills for any practitioner in critical care is the ability to communicate to families and decision-makers the final prognosis for any complex injury or illness. In my 40 years of practice, I have struggled to communicate with many families about the condition and final outcome of a loved one who has experienced a life-changing injury. And despite the evolution of medical technology, which has added much to our ability to make a diagnosis (such as magnetic resonance imaging, electroencephalographic monitoring, and flow studies), our ability to explain prognosis still comes down to communication at a very personal level based on human interactions and emotions. Since the dawn of medicine, this bond between family and practitioners has been at the core of trust, which leads to treatment decision-making.

The inclusion of quotations from both surrogates and physicians in such an article was very illustrative of the many issues we have in proper communication with the families of our patients. Sometimes we cannot truly do a self-analysis on this important skill set of medicine, which is a mixture of compassion, information, and support. We can all learn from this article.

The article by Jones et al. [1] is one of the first systematic studies on how we in the neuro-ICU should address and communicate prognostic uncertainty in patients with traumatic brain injury. The work is based on the body of thought known as the process of scientific uncertainty, which encompasses uncertainty about “diagnosis, prognosis, causal explanations, and treatment” related

to disease and was first described by Han et al. [2]. This model develops a system of ideas on uncertainty (especially issues such as a lack of long-term outcomes and prognostic data to guide decision-makers), on communication strategies of the physician, and, more importantly, on how the emotional burden of decision-makers plays a role in deciding on life-sustaining goals of care, something we deal with in our everyday practice in the neuro-ICU.

One of the key factors found in this study that should be eye opening to practitioners caring for patients with head injury was that 81% of the surrogate decision-makers described instances in which a lack of information regarding their loved one’s disease and/or prognosis created uncertainty in their ability to make decisions. This brings to light (1) how we often do not present the information in a way that can be understood by the lay public and (2) our lack to truly answer questions to clarify these key issues and decrease uncertainty. Many times I have been in situations with families in which I could sense that this uncertainty was eating at the soul of the decision-makers. Another key aspect brought up by the study was how sharing of neuroimaging findings, such as magnetic resonance imaging and computed tomography scans, helped the surrogate to understand the severity of the injury. This illustrates that this skill set of sharing and pointing out key radiologic findings to lay observers needs to be added to our fellowship programs. The ancient phrase, “a picture is worth a thousand words,” cannot be stressed enough, especially when dealing with prognostication.

One of the largest issues with this article is the small number of surrogates interviewed, and the ones who chose comfort care were limited. The question I ask is did these families have some component of guilt about comfort care that they wished not to be interviewed? This of course illustrates many issues with culture, in that

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we know various cultures deal with end-of-life planning in different ways. Some cultures may not allow so called withdrawal of care, whereas others may place the quality of life above all other concerns. Also, religious backgrounds and educational levels of families can play an important role in dealing with uncertainty. Future studies should look into this aspect. Other variables also add to issues of uncertainty. A family of physicians may feel a level certainty in their decision-making on the basis of education and experience, as opposed to a family with limited medical understanding. However, this fact also leads to us developing techniques to better educate the public on the levels of neurologic injury and the care options available for a family member. Simplification of medical information should be a skill that every intensivist has in their portfolio.

Over the years, I have also noted another aspect that was not addressed in this article: the role of the financial burden placed on the surrogates. As any social worker working in neurology can tell you, families may be shocked at the cost of skilled facilities. The burden on many families to liquidate assets, sell family homes, and protect a family inheritance may play an important role in making care decisions. I am always shocked that many colleagues are totally unaware of these aspects when they speak to families. I believe the addition of a social worker to educate both the care team and the surrogates may be something that should be added to future studies.

Overall, this article is an opening to all of us to begin addressing family uncertainty. The information in this study reinforces the aspect that education on speaking to families and techniques with dealing with surrogate uncertainty should be added to the curriculum of all neurocritical care programs. Also, I believe a team of staff created to address these issues should be in place in all ICUs.

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References

1. Jones K, Quinn T, Mazor KM, Muehlschlegel S. Prognostic uncertainty in critically ill traumatic brain injury patients: a multicenter qualitative study. *Neurocrit Care*. 2021. <https://doi.org/10.1007/s12028-021-01230-3>.
2. Han PKJ, Klein WMP, Arora NK. Varieties of uncertainty in health care: a conceptual taxonomy. *Med Decis Mak*. 2011;31(6):828–38.