Published in final edited form as:
Neurocrit Care. 2015 August ; 23(1): 127–130. doi:10.1007/s12028-014-0097-2.

Shared Decision Making in Neurocritical Care: an Unmet Need in our NeuroICUs

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Abstract

Improved resuscitation methods and advances in critical care have significantly increased the survival of patients presenting with devastating brain injuries compared to prior decades. After the patient's stabilization phase, however, families and patients are increasingly faced with "goals-of-care" decisions about continuation or withdrawal of care (WOC). While WOC is by far the most common cause of death in neurocritically ill patients, concern remains in the varying rates of WOC between centers while also raising the question of "self-fulfilling prophecies". The WOC decision is difficult and is influenced by several factors. These include the underlying severity of disease, the health care proxy's understanding of projected outcomes and their uncertainties, physician bias, a physician's poor explanation of prognosis, lack of data about patient-centered outcomes, complication risks with continued care, and the patient's and health care proxy's wishes and values.

A pressing question is whether it may be possible to remedy these issues through a disease-specific decision support intervention, potentially leading to better-informed and less biased goals-of-care decisions in neurocritically ill patients. Shared decision making (SDM) is a collaborative process that enhances patients' and proxies' understanding about prognosis, encourages them to

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Disclosures
Dr. Muehlschlegel has nothing to disclose.
Dr. Col has nothing to disclose.

actively weigh the risks and benefits of a treatment, and considers the patient's preferences and values to make better decisions. Decision aids (DAs) are SDM tools, which have been successfully implemented for many other diseases to assist difficult decision-making. In this article we summarize the purposes of SDM, the derivation of DAs, and their potential application in neurocritical care.

Keywords

neurocritical care; acute brain injury; shared decision making; decision aid

Withdrawal of care (WOC) is the most common reason for death in neurocritically ill patients[1-3] and is known to sometimes lead to self-fulfilling prophecies[2,4] and clinical nihilism in patients with acute brain injuries[5]. While disease severity and patient preferences and values should drive the decision to withdraw care from critically ill patients, families often base WOC decisions on physician prognostication[6], making them subject to potential bias. To derive an estimate of a patient's prognosis, physicians commonly rely on point-based prediction rules, past experiences, and personal biases[2,7,8].

Longer-term patient-centered outcome information is lacking for many diseases in the neuro intensive care unit (neuroICU). In addition, the communication of prognosis is not routinely taught during medical education, resulting in poor or complete avoidance of communication about prognosis and its uncertainties, as well as the assessment of patient and proxy values and preferences[9,10]. Qualitative research studies in families of critically ill traumatic brain injury (TBI) patients have revealed that families often feel "under-informed" by physicians and nursing staff, partly due to mixed or biased messages from different providers and medical services[10,11]. Especially in patients with catastrophic neurological injuries, prognosis can be inherently biased, and skewed towards a nihilistic or overly optimistic outlook[5]. As an example, in patients hospitalized with severe traumatic brain injury, recent investigations by members of the Canadian Clinical Trials group have revealed a disconcertingly high variability of WOC rates, ranging between 45 to 89%, at six Canadian level I trauma centers[3]; this considerable variability was not explained by disease severity, age, or previously diagnosed co-morbidities. In a different study of a single Level One Trauma Center in the U.S., high variability in WOC recommendations between subspecialties involved in the care of patients with TBI (Trauma, Neurosurgery, Neurocritical Care, Anesthesiology/Surgical Critical Care) was also observed[4] . Two independently conducted surveys of intensivists, neurosurgeons, and neurologists exploring determinants of prognosis and clinical decision-making in adult patients with severe TBI revealed a significant variation in perceptions of neurologic prognosis, clinical decision-making, and recommendations to patient's families[4,12]. Survey participants were given case vignettes and asked about the patient's prognosis one year later. In the Canadian study, approximately one-third of respondents agreed, one-third were neutral, and one-third disagreed that the patient's prognosis would be unfavorable at one year[12]. In a survey conducted at a U.S. trauma center, especially in younger patients, some clinicians prognosticated overly pessimistically based upon data available at the time of hospital admission[4].

For neurointensivists, outcome prognostication is part of our daily "bread and butter" work because of the nature and severity of patients admitted to neuroICUs. Therefore, the neuroICU serves as an ideal place to pilot decision support interventions that could improve and standardize the way prognosis is communicated. At the same time, because critically ill patients with brain injury may not be able to express their wishes, and because decisions about treatment depend as much on a patient's prognosis as on patient values and preferences, it is equally important to assess these concerns and related issues via the patients' proxies as part of the decision making process[13,14].

Such decision support interventions have been termed "decision aids" (DAs) and are considered to be "shared decision making" tools. A priority of the *Patient Protection and Affordable Care Act of 2010* and *Healthy People 2020*, DAs have been successfully implemented for many other diseases to assist with making difficult decisions and improve informed medical decision-making[15-17]. Examples are discharge planning for patients admitted to a general intensive care unit ("Planning Care for Critically Ill Patients"[18]), diabetes ("Should I take insulin?"[19]), or menopausal women with osteoporosis ("Healthy Bones"[20]).

Shared decision making is a collaborative process that enhances patients' and their proxies' understanding about the disease and its prognosis, encourages them to actively weigh the risks and benefits of a treatment, and assesses and matches this information to patient preferences and values, thereby decreasing decisional conflict and potentially improving decision quality and health outcomes. As two separate reviews have shown, patients want to be informed about their health condition, and many patients would like to participate in management of their disease[13,21]. Findings from the Cochrane Collaborative review of 86 randomized trials of DAs[15] show that they increase knowledge of treatment options and outcome probabilities, decision processes and quality, decrease decisional conflict, improve patient-practitioner communication, and increase medication adherence in the setting of various chronic diseases. Furthermore, and of pertinence to acute illnesses, DAs have been shown to improve accuracy of risk perception, increase knowledge about possible decisions to be made, change decisions about undergoing invasive procedures and elective surgery, and lead to more realistic expectations of treatment effects on disease outcomes. This is due in part to patients and proxies having heightened awareness and better understanding of the risks and benefits involved in making decisions.

Given this background, we propose that use of validated DAs in the neuroICU for outcome prognostication and goals-of-care decisions may offer a more streamlined and standardized way of providing prognostication and setting correct expectations, all while limiting physician bias. In the neuroICU, these benefits may be particularly relevant for critically ill patients with catastrophic neurological injuries. The patient's impaired mental status precludes independent decision making, and the proxy is asked to make decisions on the patient's behalf. This introduces additional challenges to decision-making, and provides further opportunities for decision aids to support patient's values and preferences.

Several difficult areas in which DAs might be useful in the neuroICU include making decisions about tracheostomy, feeding tube placement, and implementation of Do-notresuscitate/Do-not-intubate orders. The most crucial decision, however, involves the one surrounding goals-of-care, during which the physician asks the proxy, based on the patient's prognosis, to decide about WOC or continuation of care. The latter commonly includes a tracheostomy with gastric feeding tube placement to help liberate the patient from the ventilator, followed by rehabilitation or admission to a nursing home. A DA, which supplements rather than replaces counseling by physicians, could be used to enhance patients' and proxies' understanding about prognosis[14] derived from validated prognostication models by illustrating statistical probabilities and uncertainties of outcome, (as well as potentially required surgical procedures) in a graphical and practical way. Visual aids, including the use of cartoons, symbols, photos, or videos may play a large role in ensuring proper understanding of medical terms. For example, video DAs have been shown to effectively help patients and proxies[22] in making more informed decisions about end-of-life care and cardiopulmonary resuscitation in patients with dementia[23], advanced heart failure[24], cancer[25,26], and critically ill patients with pulmonary disease[27]. Difficult treatment decisions are derived in concert with patient's values and preferences, which include their religious, cultural and ethnic beliefs and prior experiences.

A recent Cochrane review concluded that for a DA to be effective and integrated into routine clinical care, it must contain disease-specific data that is tailored to patients and their proxies, and be simple and time efficient for physicians to use[14,15]. To our knowledge, no DAs have been specifically developed nor tested for use with any of the difficult decisions commonly made in the neuroICU.

The development and validation of DAs can be complex. An internationally approved set of criteria to determine the quality of patient DAs have been published by the International Patient Decision Aid Standards (IPDAS) Collaboration[28], and should be rigorously applied to any newly developed DA. A toolkit for DA development[29], as well as large registries of existing DAs can be viewed online at the Ottawa Hospital Research Institute[17] and the Dartmouth-Hitchcock Center for Shared Decision Making[30].

The use of DAs could provide great benefit to critically ill patients in neuroICUs. When we extrapolate objectives previously achieved by DAs involving other diseases, such as cancer[15], to potential future DAs in the neuroICU, we see several likely benefits. Improved patient outcomes can be expected through better understanding of projected outcomes and risks, reduced decisional conflict, better quality decision-making processes with potentially reduced lengths-of-stay and costs (via more rapid transitions to either rehabilitation facilities or hospice), overall improved quality of care, and possibly limited physician bias. The development and implementation of disease-specific DAs in the neuroICU will enhance the ability of physicians with varying experience to more neutrally and objectively prognosticate while also eliciting patient's values and preferences. A neuroICU DA would be a standardized prognostication tool that is publicly available for all, simple to use, easy to understand, timesaving for the physician, and applicable during rounds or family meetings.

Acknowledgments

Funding:

Dr. Goldberg is funded by NIH/NHLBI for the Worcester Heart Attack Study (5R01HL035434-30)

Dr. Shutter is funded by NIH/NINDS as a Site-PI for SHINE (1U10NS080371; Sub-Award # GC12107-138778), co-investigator for NETT Pittsburgh Clinical Hub (5U10 NS080371-03), co-investigator for “Developing Goal-Directed Perfusion Therapy for Neurocardiac Injury in Subarachnoid Hemorrhage (1R01NR014221-01A1), and Department of Defense as Co-investigator for “In Vivo Neuroimaging Biomarker Panel for Chronic Traumatic Encephalopathy” (W81XWH-13-2-0079).

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