

**WITHDRAWAL OF LIFE SUSTAINING THERAPY IN
NEUROSURGICAL PATIENTS: AN URBAN BIOETHICAL REVIEW**

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ABSTRACT

Physicians encounter significant difficulty when faced with decisions related to withdrawal of life-sustaining therapy (WLST) in patients with devastating brain injury (DBI). The complexity of this decision-making process is multifactorial, including practitioner- and patient-specific variables, as well as surrogate decision-maker bias, inaccuracies in scoring systems, and inconsistencies in guidelines endorsed by professional societies; these issues all contribute to the significant uncertainty of these situations and variability in treatment paradigm. Solutions are complex; however, analyzing WLST with an urban bioethical lens — which emphasizes the principles of solidarity, agency, and social justice — can enhance physicians' ability to navigate this uncertainty and ensure that potential solutions are patient-centered.

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CHAPTER 1: INTRODUCTION

Devastating brain injury (DBI) has been defined by the Neurocritical Care Society as neurological injury where there is an immediate threat to life from a neurologic cause.[1] Withdrawal of life-sustaining therapy (WLST) is the leading proximate cause of death in patients with DBI.[2] Evidence supporting decisions regarding WLST in the context of DBI is overwhelmingly weak, leading to variability in clinical decision making amongst hospitals. This variability in treatment paradigm stems from a complex interaction between practitioner specific variables (cognitive uncertainty, bias, personal experience, institutional practices) and patient specific variables (socioeconomic status (SES), age, race, sex, functionally dependent health status, Glasgow Coma Scale (GCS)). A major dilemma inevitably encountered in this context is whether premature WLST deprives patients of an opportunity to recover, or if consistently sustaining life in patients with DBI could subject patients to further adversity and discomfort.[3] The combination of the aforementioned variables in conjunction with this dilemma contributes to the uncertainty experienced by physicians, ultimately resulting in the variability seen in WLST decision-making.

My intentions are not to call the criteria for unrecoverable brain injury into question, but rather to suggest that there is a lack of unequivocal objectivity and profound amount of uncertainty encountered in these situations. This should serve as a reminder to healthcare professionals that prognostication is heavily influenced by practitioner- and patient-specific variables, and that many patients who have suffered a DBI can make a substantial recovery. Uncertainty complicates the ability of physicians to effectively

decide on treatment plans and communicate an objective prognosis to the family members of these patients.

An urban bioethical toolbox can be profoundly useful when navigating the decision-making process during times of uncertainty. Urban bioethics is a branch of bioethics that views health disparities as an ethical problem, which can significantly impact patient-specific variables and DBI treatment paradigms. It ensures that practitioners remain considerate towards a patient's unique background and facilitates the tailoring of care. The urban bioethical toolbox offers a strong foundation of principles upon which to build rapport and coordinate care. For example, the principle of solidarity emphasizes the healing bond between providers and patients, rather than treating them as separate entities. The principle of agency prompts us to consider the practicality of a solution within the patient's background, rather than generating a standardized list of solutions. This is because recommendations are useless if a patient's social circumstances prevent them from following them. Lastly, the principle of social justice emphasizes the need for healthcare practitioners to tailor their advice to the patient's and his or her family's background. By doing so, care providers can ensure that their recommendations are relevant and effective in addressing the patient's needs.

In chapter two, I will discuss difficulties faced during the shared decision-making process, the role that physician bias plays in the perception of prognosis, how minoritized groups are more likely to fall victim to distrust and proposed solutions, and the impact that opinions regarding "what makes life worth living" have on decision-making.

In chapter three, I will highlight the different opinions regarding WLST decision-making, how advance directives and credible surrogate decision-makers can restore

patient autonomy, the importance of keeping up with modern guidelines, expediting guideline implementation, and how artificial intelligence can augment our ability to do so. Finally, I will discuss the pitfalls of AI as it pertains to minoritized groups.

In chapter four, I will discuss discrepancies between recommendations provided by different professional societies and language issues within the guidelines.

In chapter five, I will summarize inaccuracies in scoring systems such as the Glasgow Coma Scale (GCS), Intracerebral hemorrhage (ICH) score, Hunt and Hess scale, and Fischer scale, as well as the consequences of over-relying on these scales during decision-making.

In chapter six, I will discuss core ethical principles in the context of DBI and WLST, specifically social justice and its relevance to minoritized groups and resource limitation.

Finally, in chapter seven, I will emphasize the importance of palliative care in neurosurgery and the need for palliative care and sensitive discussion training in the neurosurgical training curriculum. I will highlight the usefulness of the urban bioethical toolbox in facilitating patient-centered discussions.

CHAPTER 2: SHARED DECISION-MAKING AND PHYSICIAN BIAS

Physicians are placed in a very difficult situation. Being the point person for delivery of bad news is not a simple task. When discussing new information with a patient's family, they must be considerate towards the uncertainty surrounding a prognosis, while presenting what is objectively known about the patient's condition. Decisions to withhold or withdraw care must be shared amongst physicians and surrogate decision-makers; therefore, it is a physician's duty to inform surrogate decision-makers so that they can make informed decisions. There are two major issues that we encounter during this phase: 1) the surrogate decision-makers may fall victim to prognosis discordance between themselves and the physician, 2) the manner in which a prognosis is portrayed to a surrogate decision-maker is highly relative to the treating physicians views on "what makes life worth living." Concerningly, in a cross-sectional study of 193 patients with severe acute brain injury, prognosis discordance occurred for 61% of patients, with both misunderstanding and belief differences present; prognosis discordance was more likely for family members who were part of minoritized racial groups. Interestingly, nurses seemed to accurately predict poor family understanding, whereas physicians perceived belief differences as poor family understanding.[4]

Unfortunately, this study corroborates the existence of pessimistic view bias surrounding prognosis after acute brain injury, and supports the notion that DBI patients are at risk of falling victim to a self-fulfilling prophecy— early prognostication, which leads to early WLST and death. This stems from poor outcomes physicians have observed in similar patients who have not received aggressive therapies. This observation therefore leads to fewer patients receiving aggressive therapy and, as a result, poorer outcomes.

Differential Treatment Of Minoritized Groups

Alarming, prognosis discordance was more likely for family members who were part of minoritized racial groups.[4] This finding that differential treatment of minoritized racial groups occurs in the setting of prognostication after brain injury, further proves the complex interaction between patient- and practitioner-specific variables, which leads to variability in treatment paradigm.

In a separate major study that included nearly 38,000 patients across 825 different trauma centers in the United States found that race, geographic region, and payment status were significantly associated with the decision to WLST.[5] Compared to white patients, black patients were less likely to undergo WLST, even when injury severity was similar. Conversely, in studies looking at other clinical scenarios, black patients have been less likely to undergo treatment.[5] This discrepancy speaks to an existing lack of trust between minoritized racial groups and physicians.[6] A more comprehensive racial and cultural representation is required in the field of neurosurgery. Additionally, physicians must become more aware of the systemic distrust that exists between certain patient populations and the healthcare system.

Improving The Shared Decision Making Process: Minoritized And Beyond

The first step toward an improved shared decision-making process requires practitioner introspection and self-reflection. It is paramount for practitioners to acknowledge that race-dependent differential treatment, as it pertains to WLST after acute brain injury, exists. There is substantial research proving that minoritized racial groups and their families are more likely to experience lack of trust and dissatisfaction

with the healthcare system[6]. Physicians who are of a different race from the patient in whom they are treating, must inexcusably account for this historic mistrust and prognosis discordance, both of which are well documented. This can be accomplished by placing greater emphasis on trust-building in their plan of care, even if it requires more time at the bedside. Applying the principle of solidarity to this situation would facilitate a more patient centered approach to care. As opposed to the dynamic in which one person is unidirectionally helping another, the “solidarity lens” would argue that each party is helping each other. After all, a doctor does not exist without a patient. It humanizes the frequently intellectualized physician-patient relationship, and allows physicians to function within a mental framework that is more considerate. Even so, trust-building efforts are often curtailed by time constraints created by other clinical obligations. For this reason, if a physician cannot devote sufficient time to the process, then other members of the care team, nurses, for example, must be involved in the decision making process. After all, nurses more accurately predicted poor family understanding, which is likely directly correlated with their ability to spend more time at the bedside with the patient and their family.[4] Unfortunately, nurses are rarely involved in conversations with family regarding prognosis and decision-making; this is certainly an oversight that can be easily corrected. Finally, incorporating “independent patient advocates” who have personal experience with brain injury as survivors or caregivers may be a useful approach for providing a unique perspective that could potentially alleviate challenges related to practical and experiential uncertainties faced by surrogates and clinicians.[2] In the future, we must work towards creating a more comprehensive and interdisciplinary “news delivery team” that involves all team members involved in a patient’s care when having

these sensitive discussions. Shared decision-making should not be limited to communication between physicians and patients.

“What Makes Life Worth Living”: A Difference of Opinion

There is considerable variability in physician views on “what makes life worth living.” Therefore, there is substantial opportunity for personal opinion to be incorporated into decisions related to care of DBI patients. Opinions are introduced by care providers through their word choice during discussions with patients and their families. Prior to engaging in these discussions, surrogate decision makers have their own preconceived opinions about “what makes life worth living.” To make matters more complex, all of these opinions must be considered in the context of what the surrogate decision-makers believe the patient values are independent of their own. The interplay between these opinions creates a significant amount of complexity and contributes to the variability in treatment paradigm.

Assuming the wishes of the patient are unknown and the patient lacks capacity, the surrogate decision makers must act in the best interest of the patient. The ability of a family to accurately determine a patients best interest is heavily influenced by prognosis. When discussion is the vehicle to deliver a prognosis, bias can be introduced through the act of speaking. Depending on a physicians views of “what makes life worth living,” their perspective will be portrayed through their tone, word-choice, and their subjective impression of the potential to make a meaningful recovery, in addition to other variables. For example, with regard to word choice, the word “vegetative” has dehumanizing connotation. In fact, many organizations and task forces have begun to abandon the word

altogether in favor of terms such as “unresponsive wakeful syndrome” or “cortically mediated state.”[2] For many, “vegetative” is associated with poor prognosis and an inability to experience a meaningful life. Consequently, using such language likely contributes to pessimistic opinion formation and ultimately, the aforementioned “self-fulfilling prophecy” that results in early WLST. The impressions that surrogate decision makers form about their loved ones are heavily influenced by the perspective portrayed to them by the caring physicians during goals of care discussion. Therefore, the caring physician’s opinions and word-choice can largely shape and impact the plan of care.

CHAPTER 3: VARIABILITY IN TREATMENT PARADIGM

The difference in opinions amongst physicians with regards to “what makes life worth living” likely plays a sizable role in the variability of clinical practice of WLST across institutions. This variability is well-documented in the literature. One study demonstrated that the proportion of patients being withdrawn from life-sustaining treatment within three days of admittance to the intensive care unit varied between 30.4% and 92.9% across six level-one trauma centers in Canada.[7] A separate case scenario asked 455 intensivists, neurosurgeons, and neurologists to evaluate the prognosis of a hypothetical patient at one year. Approximately one-third of respondents agreed, one-third were neutral, and one-third disagreed that the patient prognosis would be unfavorable at one year. Strikingly, only 10% were comfortable recommending WLST.[8] Therefore, it is objective that significant variability in treatment paradigm exists between institutions. Due to patient-specific variabilities, it would be nearly impossible to standardize these discussions. Thus, a physician’s bias is always at risk of being imposed upon the patient and family for whom they are caring.

Advance Directives As A Solution

We can prevent the introduction of physician bias and uphold the principle of autonomy in times when a patient lacks capacity by utilizing advance directives. Advance directives can help prevent patients from being subjected to variability in treatment paradigm, although it is not a solution to the variability within the paradigm itself. Per the Brain Trauma Foundation, traumatic brain injury is the leading cause of death and disability in children and adults ages 1 to 44. This cohort is young, and brain injury in

many cases leaves one incapacitated; therefore, we should recommend that advance directives be drafted at a relatively young age, with the first discussions taking place between 15-18 years of age. This would ensure that a patient's wishes are respected in times of uncertainty. An advance directive should be a living document. It should be drafted while young and ideally healthy. It should be revisited regularly and modified to accommodate one's evolving values and beliefs, rather than rushed during an acute health crisis. Interestingly, one cohort study of US adults found that advance directives completed in the last three months of life were associated with a higher likelihood of aggressive care preferences. Conversely, those who prepared their advance directive one year or more before death were more likely to prefer limited/conservative care.[9] This suggests that advance directives completed within the last few months of life may be more influenced by fear and the opinions of others than by a person's true values and beliefs. Just as important as the document itself are the conversations that we have with our loved ones about how we would like to be cared for at the end of life. As previously mentioned, the surrogate decision-maker must act in the best interest of the patient. If the two parties hadn't engaged in regular discussion about their wishes, then the surrogate decision-maker may not be well-versed in the values of the patient. In this situation, the credibility of the surrogate as a patient advocate is diminished. Required advance directives would minimize rushed decisions at end of life by physicians and families trying to act in accordance with the perceived true wishes of the patient. Nonetheless, physicians must still make many difficult decisions in the context of death and dying, one of those being the decision to create a safe space to talk about death. Speaking about death is uncomfortable for many healthcare providers and patients alike. Unfortunately,

death is frequently spoken about solely with those at risk of dying, and not with healthy individuals. Because of this discrimination, death has become stigmatized rather than normalized as a natural process. If death was a topic routinely spoken about at annual check-ups (once reaching a certain age, say 15-18 years old), the same way that we speak about vaccination and screening, then stigma surrounding death would likely not exist.

Staying Up To Date On Professional Society Guidelines

Although multiple professional societies recommend early aggressive resuscitation while avoiding early WLST, a substantial amount of patients have care withdrawn within 72 hours of admission for DBI.[3], [10], [11] A study published as recently as 2021 showed WLST before the 72-hour recommendation occurred in over 50% of patients with DBI.[3] In addition to pessimistic bias contributing to early WLST, there is a delay between the release of new recommendations (recommending against early WLST) and their practical application in clinical practice. For example, the 2010 American Heart Association/American Stroke Association (AHA/ASA) intracerebral hemorrhage (ICH) guidelines recommended aggressive treatment and against early do-not-resuscitate (DNR) in patients presenting with ICH. A large, multi-center study looking at practice patterns between 2010-2019 found that a delay in WLST was not observed until these recommendations were reiterated in the updated 2015 AHA/ASA ICH guidelines.[3] Therefore, in addition to the bioethical complexities that exist within the context of this issue, logistics (such as delayed adoption) may be equally obstructing. Guidelines form the foundation of standard of care, therefore not keeping up with these guidelines could be considered negligent. However, it is also important to consider that

poor communication or distribution of guidelines and lack of specificity in recommendations, in conjunction with significant inter-patient variability, can affect the general adoption of new practices.

Expediting The Implementation of Professional Society Guidelines

The adoption of new guidelines can take varying amounts of time at different institutions; therefore, in the future, we should assume there will be a delay between the release of new guidelines and the time it takes to implement them. To combat this, institutions should strongly consider mandating department-specific research panels that keep track of new recommendations and highly impactful literature. This panel would meet regularly to help consolidate new literature, vote on papers that are most impactful, and ensure that this literature is being incorporated into patient care. Individual physicians are obligated to keep up with new literature, but this panel would be supplementary. Resident-led journal clubs are an academic institutions best effort at this, but attendance to these sessions is highly variable. Community hospitals lacking residents have no formal infrastructure for didactics and continued learning activities. Therefore, such a panel could ensure that important guidelines and literature are not being overlooked, guarantee the timely enforcement of new recommendations, and help standardize care within a department. Although, variability in treatment may continue to occur across institutions, standardizing treatment within an institution is a good first step.

Artificial Intelligence In the Electronic Medical Record.

In the future, I believe that an Artificial Intelligence (AI) platform programmed to perform a similar function as the aforementioned panel will exist. Ideally, it would regularly scan through available literature, and consolidate articles and recommendations made by major journals in all fields of medicine. A huge advantage of this AI would be that its technology could be licensed to lower resource institutions to avoid the need to hire more employees to create said panel. Additionally, I believe there will be major applications for AI in electronic medical record (EMR) platforms that we currently use. This AI software will ensure that the treatment being recommended by physicians is supported by up-to-date literature. For example, if a physician is placing an order related to WLST within 72 hours of a patient being admitted, a disclaimer citing peer-reviewed literature would appear either supporting or refuting the physician's decision. Each time a patient is admitted with a DBI, the platform would record the time and date of admission and, eventually, the time and date that care was withdrawn. One could subsequently create an algorithm programmed to notify both the physician and an overseeing administrator if there is an increasing number of patients having WLST within the first 72 hours of admission. This would allow care teams to more efficiently identify and correct systemic issues, rather than relying on retrospective studies to highlight these discrepancies. We must work toward generating real-time data that highlights time between admission and WLST through multi-center studies, and incorporate these findings into a national database. This database would allow us to verify whether or not these recommendations are being applied to practice in real-time and make additional efforts if they are not. Nonetheless, AI is very imperfect and has the power to do damage

just as much as do good. The next section discusses some of these imperfections and highlights why we must scrutinize algorithms particularly as they pertain to minoritized groups.

Urban Bioethics And Major Pitfalls In AI Technology.

Unfortunately, racial bias is perpetuated by many of the commercial algorithms used by the U.S. healthcare system to guide health decisions. Placing a greater emphasis on urban bioethics during the development of these algorithms can potentially mitigate this bias. For example, the principle of "agency" encompasses two fundamental dimensions of human decision-making. Firstly, it refers to our cognitive prowess to envision and comprehend the full spectrum of alternatives that can potentially exist in a given circumstance. Secondly, it pertains to our practical proficiency to execute a chosen course of action from among the options available to us. Without the practical means to execute a course of action, that course of action is useless to consider. The concept of agency is important to consider when designing decision making tools. If a tool makes recommendations that don't account for patients with limited access to care, and, therefore limited agency, the tool would be both ineffective and biased. For example, a major commercial algorithm, which utilizes healthcare costs as a proxy to predict healthcare needs, demonstrated that black patients generate lesser medical expenses than white patients, given the same medical condition and accounting for specific comorbidities.[12] One misleading assumption from this result is that black people are healthier. However, the algorithm failed to account for decreased access to care and distrust towards the healthcare system, which disproportionately impacts the black

community; this leads to decreased healthcare utilization and, ultimately, less healthcare spending. Although this error has since been corrected, it is highly probable that other algorithms currently in use fail to account for racial bias and limitations in patient agency.

The failure in the aforementioned example could be attributed to an oversight in the design of the algorithm. But what if an algorithm begins carrying out unintended tasks? A recent study found that an AI tool designed to analyze radiographic imaging, began discerning patients self-reported race with profound accuracy, despite the image having no patient information associated with it.[13] Frighteningly, the investigators were unsure as to how the AI was performing this task, and therefore could not fix this feature. If the AI's ability to discern race became a core part of its decision making capacity, it could produce race-specific errors that would likely be undetectable by radiologists.[13] Users and developers of AI must proceed with extreme caution. Although there is promise, misused AI and machine learning can perpetuate or even worsen the well documented racial disparities that exist in medical practice.

CHAPTER 4: AMBIGUITY IN PROFESSIONAL SOCIETY GUIDELINES

It is important to note that there are sometimes discrepancies between recommendations provided by different professional societies. The 2015 Neurocritical Care Society position statement discusses prognostication, psychosocial, and ethical management of DBI. [1] The 2016 Brain Trauma Foundation includes a comprehensive breakdown of how to manage severe TBI, but fails to address both WLST and the inadequacies of prognostication. Lastly, with regards to its structure, the 2015 AHA/ASA ICH guidelines were a combination of these two; it discusses the specifics of medical management while including a brief statement related to the ethics of WLST and issues that arise from early prognostication. [14]

Prognostication, psychosocial variables, and ethical considerations are impossible to separate from medical considerations as they pertain to management of DBI. I like to think of prognostication, psychosocial variability, and ethical management of DBI as the “art” of medicine, and medical management as the “science” of medicine. In their attempts to create comprehensive guidelines, organizations must consider both the art and science of medicine. An example of this integration is seen in the 2015 AHA ICH guidelines.[14] Recommendations account for bias that is introduced into the decision making process by our current prognostic models and scoring systems, while still providing practitioners with evidence-based medical guidelines.[14] A major point of emphasis is the fact that no prediction models have accounted for the impact of limitation-of-care decisions (do-not-attempt-resuscitation (DNAR) orders) or for WLST and are therefore incomplete. In fact, current outcome prediction models are overly pessimistic because of their failure to account for care limitations within their

calculations.[14] They point out that DNAR orders are a proxy for overall lack of aggressive care, particularly when administered early after ICH. To no surprise, overall aggressiveness of ICH care is associated with patient outcomes, even after controlling for individual characteristics. Therefore, one can infer less aggressive care early after ICH leads to poor outcomes. Consequently, if DNAR orders are assumed to be a proxy for overall lack of aggressive care, and lack of aggressive care leads to poor outcomes, then DNAR orders result in poor outcomes. Interestingly, early DNAR orders are associated with doubling the hazard of death independent of basic demographics, location, intraventricular hemorrhage, and ICH volume.[3] Therefore, due to our inability to generate reliable prognoses, these AHA guidelines recommend early aggressive care after ICH onset. Specifically, postponement of new DNAR orders until at least the second full day of hospitalization. While I agree that WLST should be postponed and aggressive resuscitation pursued, professional societies must agree on the length of time of resuscitative efforts. Discrepancies in what is recommended by major guidelines can very likely lead to variability seen in the treatment paradigm of WLST and acute management of DBI patients. In contrast to the AHA guidelines, the Neurocritical Care Society guidelines recommend at least 72 hours of resuscitation before considering the withdrawal of care. A full 24 hour difference between these recommendations is significant, especially during such a critical window. I would like to point out that guidelines should not replace physician judgment with respect to particular patients or special clinical situations. But with regards to WLST, these decisions should be delayed more frequently than they currently are and the minimum time window for aggressive resuscitation should be agreed upon by professional societies. Professional societies and

organizations making recommendations on this matter must collaborate and come to a mutual agreement. The lack of uniformity can be confusing for care providers and lead to inconsistencies in the treatment paradigm. These things aside, I would like to acknowledge the honesty demonstrated by the authors of both sets of guidelines. It is profoundly difficult to make recommendations about such a controversial area of medicine. Their willingness to openly discuss inaccuracies in our ability to prognosticate is commendable. Particularly, I value their consideration of the role that scoring systems play in prognostication and how inaccurate they can be if not used appropriately.

Issues With Non-Specific Language in Guidelines

Overall, the guidelines reviewed are largely considerate. However, when faced with a controversial topic (such as the early management of patients presenting with DBI), the language used by the authors (i.e. “aggressive treatment”) becomes non-specific. Unless explicitly defined, physicians can have varying opinions on what is considered to be “aggressive treatment,” similar to the way they can have varying opinions on “what makes life worth living.” This variability can have a profound impact on the treatment delivered. The authors are not the ones to blame; rather, there is a significant lack of high-quality evidence and randomized studies to support any specific intervention as the standard of care. In order to work towards standardizing the treatment paradigm, it is imperative that we standardize language used to discuss these matters. For example, the words “aggressive” and “heroic” are both used at different points in the Neurocritical Care Society position statement.[1] These guidelines implicitly ask practitioners to determine objective treatment based on a vague, emotionally charged

spectrum of “aggressive” to “heroic.” Forcing practitioners to define “heroic treatment” in an acute setting intrinsically requires practitioners to make a prognosis. Interestingly, premature prognostication in the acute setting is contradictory to the aforementioned guidelines, which recommend at least 72 hours of resuscitation before considering the withdrawal of care. This recommendation is based on evidence that demonstrates unreliability and inaccuracy in early prognostication.[1] In summary, the standard of care should be provided for the first 72 hours at a minimum. Only when it is apparent that prolonging treatment is prolonging suffering should withdrawal of care be considered.

CHAPTER 5: INACCURACIES OF CLINICAL SCORING SYSTEMS

Scoring systems, such as the Glasgow Coma Scale (GCS), ICH score, Hunt and Hess score, and the Fisher scale are frequently used to assist with decision making; particularly in the acute setting. Overreliance on these clinical decision making tools likely contribute to early WLST. Two issues frequently at play are 1) the scales being used incorrectly and 2) the intrinsic unreliability of the scales themselves. The aforementioned scoring systems were founded on the basis of population outcomes at the time of their inception; their unreliability stems from the fact that they do not account for modern advancements in medicine. Additionally, while these scoring systems have proven helpful when looking at cohorts of patients, they are imprecise and inaccurate when applied to individuals.

Glasgow Coma Scale (GCS)

To start, GCS is the most widely accepted and utilized tool to grade level of consciousness. The total score is a sum of each of its parts; eyes, verbal, and voice. A maximum of four points can be granted for “eyes,” five points for “verbal,” and six points for “motor” for a total of 15 points. It is important to point out that two scores with the same total sum can have different clinical and prognostic implications depending on the score breakdown. For example, if a patient presenting with a subarachnoid hemorrhage (SAH) is awarded a total score of 14, with a one point deduction for eyes not opening spontaneously, that patient is likely to have a better prognosis than if that same person were to present with a score of 14, but this time with a one point deduction for

confusion. If the GCS is not itemized or presented as a sum of its individual parts, then the scores can be misleading and, ultimately, unreliable.

Intracerebral Hemorrhage (ICH) Score

Next, is the ICH score, which is a prognostic model for predicting mortality among patients with spontaneous ICH; it utilizes GCS, age, ICH volume, presence of intraventricular hemorrhage, and origin of ICH. Interestingly, a prospective, multicenter, observational cohort study found that avoidance of early DNR in the first 5 days after ICH resulted in a substantially lower mortality than predicted by the ICH score.[15] Based on ICH Score prediction, the expected overall 30-day mortality rate in this study cohort was 50%. Observed mortality was substantially lower at 20.2%.[15] This example illustrates that other variables, DNR status, for example, can influence the accuracy of the ICH score. In fact, larger studies looking at populations that were less inclined to withdraw care showed that there was a decrease in the predictive accuracy of the ICH scale.

Hunt and Hess Scale

The Hunt and Hess scale, which is designed to classify severity of subarachnoid hemorrhage and predict mortality, includes five classes, each with spectrum-based presentation criteria: for example, the severity of headache, the degree of alteration in mental status. It is no surprise that this scale demonstrates limited ability to accurately predict mortality due to score variability between users. The interobserver variability (0.42) is so low that it would likely prevent this grading system from being accepted and largely adopted if it were to be introduced today.[16] Despite this, the Hunt and Hess

score is frequently used on admission, which has great potential to impact a physician's perspective on the patient's prognosis and, transitively, his or her treatment. In fact, studies of accuracy found that many "poor grade" patients achieve good recoveries and that assessments repeated on the day of operation proved to be of more prognostic value than initial values on hospitalization.[16]

Fisher Scale

The Fisher scale was originally designed to predict risk of cerebral arterial vasospasm in patients with aneurysmal subarachnoid hemorrhage (aSAH) based on radiographic distribution of subarachnoid hemorrhage. The Fisher scale was proposed in 1980, when imaging was of substantially lower resolution; the measurements of clot size denoted in the scoring system referred to actual measurements on printed CT scans and had no correlation to actual clot thickness. Additionally, the scale does not account for clot density or variability in patient specific clearance rate. These deficiencies likely reduce the accuracy of the score. Further, while rates of vasospasm (as predicted by the Fisher scale) do not predict clinical outcome, the Fisher scale often impacts physicians perspective on outcome; for this reason, it is truly important to understand the applicability and limitations of scoring systems.

Overreliance on scoring systems is likely related to their ability to conveniently provide clinicians with quantitative data that assists with clinical decision making in the setting of uncertainty. Evidently, if used incorrectly, these scoring systems may be falsely conferring a sense of certainty.

CHAPTER 6: CORE PRINCIPLES OF MEDICAL ETHICS IN WITHDRAWAL OF LIFE SUSTAINING THERAPY

The overwhelming amount of diagnostic and prognostic uncertainty coupled with confounding cognitive biases of physicians deems the “four core principles“ of medical ethics (autonomy, non-maleficence, beneficence, and justice) extremely unreliable during acute management of patients with DBI. One could argue that pursuing treatment may be justified through the principal of beneficence, while others may argue that withdrawing or withholding care could be supported by the principle of nonmaleficence. Neither of these decisions can be objectively proven correct nor incorrect; therefore, the inevitable ambiguity that results from this dilemma makes decisions supported by these principles difficult to standardize. Interestingly, although these core principles are unreliable, they have been used for the development of guidelines related to DBI management. The Neurocritical Care Society cites the principle of distributive justice specifically to identify organ donation as a variable to consider in the context of DBI decision making. Although they acknowledge that accounting for distributive justice is challenging because of the inherent inaccuracy of early prognostication, the guidelines proceed to state that “If treatment is considered heroic and of such intensity that it limits resources for patients with greater chances of recovery, the obligation of aggressive early resuscitation may be relaxed.”[1] The guidelines do not provide any definition of what is considered to be heroic, nor do they offer an opinion on parameters that would deem a patient unsalvageable. This once again puts the physician in a position to decide when “relaxing” resuscitative efforts in the acute setting is appropriate, a decision that requires one to prognosticate early on. Additionally, this decision will likely vary based on personal

beliefs, bias, and previous experience. With regards to resource limitation and organ donation, if physicians are trained to consider patients as potential sources of organs to be donated, then those suffering from DBI in resource limited areas are particularly vulnerable of being subject to less aggressive treatment. This interpretation is supported by the fact that the guidelines explicitly state, “When resources allow, all DBI patients without a known pre-existing objection to treatment should be aggressively resuscitated for an initial period.” Does this imply that when resources are less available, a patient suffering from DBI should not be aggressively resuscitated for an initial period? I understand that resources are in fact limited under certain circumstances, but this phrasing provides room for subjectivity to be introduced into the decision making process. I believe that ambiguity in the guideline language contributes a significant amount to the variability seen in treatment paradigm, and, therefore has implications on how patients are ultimately treated.

Social Justice: Minoritized Groups And Resource Limitation

While guideline language is relatively easy to modify, there exists a deeper and less modifiable issue — decreased access to care. Access to care in the context of resource limitation should be understood within the context of the urban bioethical principle of “social justice.” When distributing resources, social justice as a principle necessitates that we take into account contextual and structural disparities. If minoritized racial groups disproportionately make up the population within resource limited areas, then they will also be disproportionately impacted by higher rates of “relaxing” early aggressive resuscitative efforts. Future studies exploring differential treatment of minoritized groups

who have suffered DBI must account for resource limitation, and social justice in general. If studies fail to account for social justice, morbidity and mortality related to resource limitation and other social factors would be misattributed to a secondary cause. Research has the power to perpetuate structural issues by disguising the true cause. We must critically challenge research design and our own beliefs and advocate for the underserved when generating new studies.

To conclude, a substantial amount of variability exists in the treatment paradigm of WLST in patients with DBI across institutions.[10] It is paramount that we consider how the authors of these guidelines arrived at their conclusions and critically analyze the logic that they used to do so. Studies that fail to account for social factors when generating their variable of interest will have highly questionable validity. Guidelines that fail to account for social factors when generating recommendations would be of questionable use.

CHAPTER 7: PALLIATIVE CARE IN NEUROSURGERY

Equally as challenging as the decision to withdraw or withhold care, is compassionately delivering bad news to a patient's family. Despite its profound relevance to neurosurgical care, it is severely underemphasized in neurosurgical training. Palliative care (PC) skills must be considered essential tools in the neurosurgical toolbox. These skills involve recognizing which patients necessitate PC, evaluating a patient's and their family's comprehension concerning his or her illness, educating patients, establishing trust, managing symptoms, attending to the needs of families and caregivers, discussing end-of-life care, and identifying when to refer patients to specialists.[17] Complicating matters even further, these discussions must account for each patient's unique social circumstance and background. Tailoring care is central to urban bioethics, and so urban bioethical principles should be considered when aiming to deliver compassionate and patient centered care. The ability to thoughtfully discuss serious illness with a patient and his or her family is a central part of compassionate care. Therefore, a surgeon must be trained to operate with his or her words, just as her or she is trained to operate with a scalpel; this skill should be developed during neurosurgery training and sharpened in the years thereafter. The urban bioethical toolbox — which contains principles such as agency, social justice, and solidarity— can be used by physicians to guide sensitive discussions in a patient centered manner.

In a survey looking at neurosurgical resident experience with teaching activities related to serious illness communication and palliative care, the majority of participants stated that they had not received any formal instruction on various topics.[18] These included elucidating the risks and benefits of intubation and ventilation (69%),

formulating prognoses in neurocritical care (60%), and leading family meetings (69%). Additionally, 48% of respondents mentioned that they "would benefit from additional communication training during their residency." Interestingly, the majority (87%) also stated that they experienced moral distress, indicating that they "participated in operations and worried whether surgery aligned with patient goals." [18] Neurosurgeons are confronted with PC related dilemmas daily. Therefore, these findings are unacceptable. It is imperative that PC training become a mandatory prerequisite for not only graduating neurosurgical residency, but entering residency altogether. These are not skills that should be learned exclusively "on the fly." Imprecision of words during sensitive patient discussions can leave lasting impressions on patients and their families. These impressions, whether good or bad, will be viewed as a reflection of the hospital. Thus, it is in the best interest of both the patients and the institution as a whole to support efforts to improve physician- patient communication.

The lessons learned by residents during "breaking bad news" training sessions are lasting. In fact, one study looked at the long-term impact of these training sessions on a cohort of pediatric neurosurgery trainees. They discovered that after a mean of 4.5 years of follow-up (range 3–6 years), 71% of trainees in the study fully remembered the session. [19] Additionally, most of them (86%) reported a positive impact of the training on their career, and all of the participants wanted more training sessions. [19] Care must be patient centered, and knowing how to navigate difficult discussions skillfully can significantly mitigate patient and family anxiety while drastically increasing patient satisfaction. Therefore, we must make "breaking bad news" training sessions a mandatory part of the annual Neurosurgery Boot Camps attended by all incoming

neurosurgery interns. This requirement would ensure that all incoming neurosurgery residents are entering training with fundamental PC knowledge and skill. Furthermore, this training should be required as a part of continuing education for senior residents, as well as attendings.

CHAPTER 8: CONCLUSION

WLST is the leading proximate cause of death in patients with DBI.[2] There is a substantial amount of variability in clinical decision making amongst hospitals, and even within a hospital. Existing evidence supporting decisions to WLST is profoundly weak, and formal training on the matter is weakly emphasized. In addition, guidelines released by professional societies use language that is non-specific and make recommendations that are inconsistent with one another. Inevitably, neurosurgeons are put in a position to make treatment plan decisions in the acute setting without having a reliable means to prognosticate. Scoring systems can be undependable and physician bias can be excessively pessimistic. Therefore, early WLST is likely related to a physicians inability to reliably generate a prognosis combined with cognitive uncertainty faced by the physicians. Adding to the complexity of the decision-making process, physicians must challenge their own internal biases and their opinions of “what makes life worth living,” while remaining considerate towards the sentiments expressed by surrogate decision-makers. The urban bioethical toolbox can be profoundly useful when navigating the decision-making process during times of uncertainty. It ensures that practitioners remain considerate towards a patient’s unique background and facilitates the tailoring of care. Decision-making is a shared process, and trust-building is a component that must not be neglected. Specifically, physicians must acknowledge barriers to physician-patient trust faced by minoritized groups and approach conversation with heightened sensitivity. “News delivery teams” should be interdisciplinary and diverse. All members of the care team should be allowed input throughout the decision making process and involved in family discussions. Lastly, palliative medicine and “breaking bad news” training must be

a mandatory component of neurosurgical training. It is not a skill that trainees should be expected to learn “on the fly.” While WLST decisions will always remain difficult, increased awareness of guideline inconsistencies and internal biases can result in the development and integration of more fair and compassionate practices and, ultimately, improve patient outcomes.

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