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Ethical Considerations in Chronic Brain Injury

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Abstract

A growing number of individuals are living with chronic traumatic brain injury. As these individuals and their families attempt to reintegrate into their communities, several ethical questions arise for clinicians and researchers. These include issues around alignment of perspectives and priorities, as well as responsibilities for ongoing treatment, education, community outreach and research. An action plan for addressing these questions is outlined.

A chronic traumatic brain injury (TBI) is one that results in longstanding sequelae that may include cognitive deficits, motor impairment, mood and psychiatric symptoms, and secondary medical conditions [1, 2]. These sequelae can range from mild to very severe, and can change dynamically over time. Individuals living with chronic TBI may experience challenges in all aspects of functioning, affecting both the individual and family. Discussion

of ethical issues regarding TBI has largely focused on medical management, particularly concerning individuals with disordered consciousness [3]; and end of life considerations after TBI[4]. Less has been written or discussed on ethical issues pertaining to living and participating in the community with chronic moderate to severe TBI, which is surprising given the breadth and scope of ethical challenges. This article identifies central ethical questions facing clinicians and researchers working with individuals living with persistent TBI sequelae and their families: When making clinical decisions, do we consider the chronic challenges, and related expenses, the individual and family will face? Do our clinical and research priorities align with the perspective of those living with the effects of chronic TBI? What is our responsibility to facilitate and optimize life after injury through treatment, education, community outreach, and research?

Nearly half of those who are hospitalized for TBI have long-term disability[5]. Common unmet needs include community-based resources, information about prognosis and long-term outcomes, assistance with school or job re-entry, treatments for TBI-related symptoms, financial assistance, and information about home-based services and assistive equipment[6–10]. For individuals able to participate in the community, unmet needs impact both the individual and family; for those unable to participate, such needs fall upon family caregivers. TBI sequelae can have a profound effect on the family [11]. Family needs, and the ability to fulfill those needs, change as time progresses after the injury [12]. Families and caregivers report the need for information, support, and medical or community resources following their loved one’s injury. Although some of these needs are addressed during acute rehabilitation, families may not feel prepared to deal with persistent challenges. Family members report significant needs for instrumental and emotional support[13], which influences how well they respond to the chronic consequences of the injury[14]. They also report difficulty coping with chronic TBI challenges. and advocating for the needs of a loved one who may not be able to advocate independently for him or herself[15]. More than half of caregivers report feeling unprepared and lacking necessary information[16].

In discussing the ethics of a chronic condition, it is impossible to ignore the fact that funding impacts the quality of treatment and its outcomes, including quality of life. In the case of TBI, emergent lifesaving care is provided universally, followed by narrowing expectations and resources as time progresses post-injury, with wide disparity across individuals. Several factors influence care access and quality that, one might argue, should have no bearing on these clinical decisions. These include advanced age, type of insurance coverage, immigration status, availability of secure housing and social supports. TBI outcomes are heavily influenced by the expertise, intensity, duration, timing, setting and scope of rehabilitation, as well as the availability of follow-up services [17–24]. In many cases however, what is “best” for a patient living with severe TBI-related deficits and his or her family is tempered considerably by the resources available. Services are often “front-loaded” and often not sufficient for the potential long-term physical, behavioral, and emotional consequences one may experience over a lifespan.

An inherent challenge faced by clinicians working with conditions whose outcomes can vary tremendously is deciding what to tell a patient and family regarding prognosis. Clinicians have the power to frame these discussions based on their own perspective or bias. As

rehabilitation providers, our perspective may be framed by our desire to maximize functional independence and life quality. Factors like hope and optimism can have a nontrivial impact on therapeutic engagement and rehabilitation outcomes[25]. However, it is not uncommon, for patients and families to be told during acute care that the person with TBI may never walk, talk, return to school, or work again[26]. Presumably these prognoses are rendered with the good intention of helping the patient avert failure or disappointment, or to allow for often-necessary life planning in light of a new-onset disability[27]. Even within a family, expectations about a TBI survivor's abilities and needs can be widely discrepant, such that the person with TBI may either be blamed for not trying harder or chided for striving to accomplish things that others view as unattainable or unsafe. Recognizing that TBI is an extraordinarily heterogeneous condition, there are no universally applicable "correct" answers to these questions.

Adding another dimension to the ethical questions surrounding prognostication and goal-setting after chronic TBI is the possible disconnect between professionals, patients and families regarding what constitutes a "good" outcome. This may represent bias or a value choice of what constitutes the good. Individuals with TBI may view providers as lacking understanding of the long term challenges associated with TBI [28] and report that professionals misdiagnose or dismiss chronic TBI symptoms [29]. Professionals are trained to approximate normality in the context of mobility, speech, cognition, and other traditional foci of rehabilitation medicine. The injured individual and family may view normality in the context of return to activities and roles related to existential factors such as **play** (leisure/enjoyment), **love** (relationships), or **work** (purpose and meaning in life)[30]. Well-intentioned, evidence-based recommendations from professionals may not align with the individual and family's priorities or long-term aspirations. Individuals may leave rehabilitation with practical skills for daily life, but may not be prepared to live well and thrive as an individual with a long-term disability. Families may not be prepared for the changes in roles, impact of daily caregiving, financial stresses, and psychosocial loss.

The field of TBI rehabilitation has made progress in the development and validation of cognitive, behavioral and functional interventions, and yet relatively few treatments are supported by stringent empirical evidence. Some evidence suggests that inadequacy of outcome measures may be at least partially to blame[31]. Traditional TBI outcome measures include domain-specific performance-based objective tests, which may or may not align with patient-reported outcomes [32] (which have excellent reliability after TBI)[33]. It is therefore unsurprising that evidence-based recommendations from professionals may not advance the individual's priorities or long-term aspirations. If our research priorities are not reflective of the outcomes and abilities that are most important to those living with persistent TBI, investments in clinical trials will not yield meaningful improvements for the people who are intended to benefit from the interventions.

The community's expectations about recovery and long-term outcomes after TBI are often informed through news stories, movies, and healthcare advertisements portraying stories about life after TBI[34]. These portrayals seem to involve either the miracle recovery or the heartbreaking tragedy; shaping the way people interact with those living with brain injury and coloring the viewpoints of policymakers, employers, and the general community.

Researchers and clinicians alike are faced with uncertainty about how to accurately translate research findings and clinical science to lay audiences.

CALL TO ACTION:

As rehabilitation professionals, we are increasingly able to save lives and improve function for individuals after TBI. Along with these treatment successes comes an ethical responsibility to remain vigilant to the lifetime needs of individuals living with TBI. This requires us to challenge societal beliefs and biases, and engage in open and honest dialogue about brain injury with all involved. We must consider our patients in the broadest perspective as active community members living with disability over a lifetime. We suggest several important steps toward this enhanced perspective.

- Rehabilitation professionals should consider long-term financial costs, and contribute to state and federal advocacy efforts to expand funding for community-based services including in-home nursing care, special education, behavioral health, respite, and case management[35];
- Rehabilitation researchers should invite individuals with chronic TBI, their families and caregivers to be engaged in all stages of research to ensure that their needs and values are reflected in the research conducted as well as the interpretation and implementation of findings. Outcome measures should include qualities that are important to these individuals;
- Rehabilitation professionals can influence society's perspective by engaging in open dialogue about brain injury within their own communities (including neighborhoods, social networks, school systems, etc.) and encouraging the narrative that each individual living with TBI has a unique story and a unique place in the community. We can shape the way people interact with those living with brain injury, including policymakers, employers, and the general community;
- Rehabilitation researchers should invest in translating research findings regarding the lifetime needs of individuals with TBI for professionals, individuals and families, and the broader community. Proposed educational topics of high priority are summarized in Table 1. Individuals living with TBI should play a key role in providing this training.

This call to action is consistent with a social disability model, which should be incorporated as part of the continuum within the TBI community. Within this model, disability is not just defined by an individual's impairments but also by how society responds to the individual; acknowledging that people with disabilities are valued as part of our diverse society [27, 36, 37]. As formal rehabilitation ends, it is our ethical responsibility to help individuals with chronic challenges transition from a medical disability model (in which disability is seen as a medical problem to be fixed) to a social disability model, acknowledging that chronic challenges may remain, and providing information, skills and resources for integrating back into the community with a disability. Education and support regarding living life with a TBI should be provided before, during and after the transition from rehabilitation. The onus for

this resource provision is on rehabilitation professionals, as individuals and families may have difficulty grasping the need for long-term supports until they have returned to the community when the challenges of chronic TBI are more apparent. Rehabilitation professionals must partner with patients and their families, community agencies, federal research funding agencies, public and private health insurance carriers, policy makers and other relevant stakeholders to build a system of care, support and inclusion across the lifespan.

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Table 1:

Proposed Educational and Training Needs by Group

Group	Proposed Educational and Training Needs
Professionals	<ul style="list-style-type: none"> • chronic TBI challenges, costs, and needs • person-centered treatment planning • the role of existential factors in health outcomes and quality of life, including the importance of love, work and play in seeking a quality life
Individuals with chronic TBI and families	<ul style="list-style-type: none"> • health management and lifestyle changes to minimize chronic TBI challenges • psycho-social coping • self-advocacy skills including information regarding long-term needs, community resources, legal rights, and assertive communication strategies • peer education and training, allowing the opportunity to learn from the experiences of others
Community	<ul style="list-style-type: none"> • how to supportively respond to chronic TBI challenges to maximize inclusion and participation • The potential contributions individuals with chronic TBI can bring to the community

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