

THE TBI EXPERIENCE: PATIENT, CAREGIVER, AND PROFESSIONAL PERSPECTIVES
ON TRAUMATIC BRAIN INJURY TREATMENT AND REHABILITATION

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Introduction

Overview

Traumatic brain injury is widely understood as a severe, debilitating condition that can drastically alter the physical, cognitive, and emotional capacities of the victim. Despite this, the meaning and effects of TBI are often interpreted and acted upon in different ways – thus frequently giving rise to conflict and misconception in regard to how TBI is experienced, treated, and healed among the involved parties; particularly betwixt the patient and care provider. In this paper, I will examine and compare through an anthropological lens the lived experience of a traumatic brain injury (e.g. patient, caregiver, etc.) with the professional experience (e.g. medical practitioner, alternative medicine practitioner, folk healer, etc.), aiming to summarize the multi-perspective mental and behavioral phenomena of TBI treatment and rehabilitation. Within this analysis, I will focus on addressing three main questions within the two experiences:

1. What is the definition of a traumatic brain injury?
2. What does adequate treatment look like?
3. What does it mean to be healed from a traumatic brain injury?

In respect to the three queries listed above, I will identify the sociocultural factors that have caused or influenced the varying perspectives and how this influences the relationship between the two groups. My research is principally grounded in a combination of an independently-conducted survey of 25 respondents sourced from online TBI support groups, as well as a broad literature review to aid in my analysis of these data. Through these methods, my objective is to harness a better understanding of the overall TBI treatment and rehabilitation experience.

Definitions

In accordance with medical anthropologist Arthur Kleinman's work and the purpose of this paper, the health care system functions as nothing less than a cultural system, "a system of symbolic meanings anchored in particular arrangements of social institutions and patterns of interpersonal interactions" (Kleinman 2013, 24). Thus, the system functions as a product of how people in tune with various social and cultural contexts understand, label, explain and treat sickness (Kleinman 2013, 26). In respect to both the patrons who live and work with a traumatic brain injury, each individual differs in how they consciously understand, accept, and adapt to the social norms of the environment in which they are placed for treatment, thus affecting "the way in which [they] think about and react to sickness and choose among and evaluate the effectiveness of the health care practices available to them" (Kleinman 2013, 38). This evaluation is heavily contingent on a variety of personal demographic factors, including but not limited to class, education, religion, ethnicity, and occupation (Kleinman 2013, 39).

These concepts are inclusive of the concept of social reality; the sphere within most of my analysis will be carried out. However, also relevant to this research are Kleinman's separations between psychological reality, "the inner world of the individual"; biological reality, "the intra-structure of organisms, including man"; and physical reality, "the material structure and spaces making up the non-human environment" (Kleinman 2013, 41). These all play an important role in being able to identify the source of and to digest individual/group thought, behavior, and norms within a clinical setting.

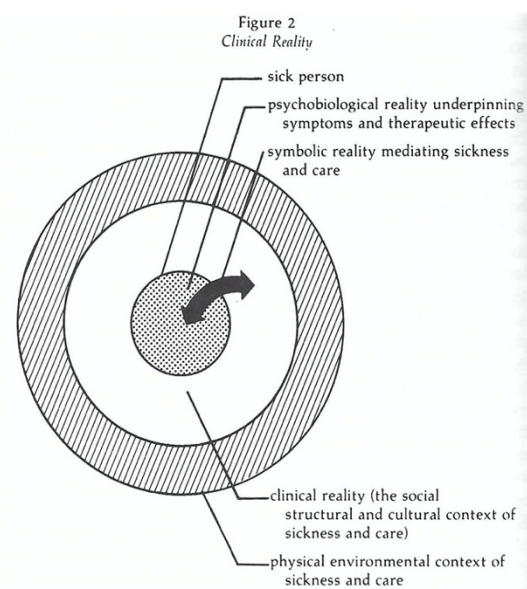


Figure 1: A. Kleinman, *Clinical Reality*, 2013, in *Patients and Healers in the Context of Culture* (Berkeley: Univ. of California Press, 2013), 42.

Finally, it is crucial to more specifically identify the key actors within both the lived and professional experiences of traumatic brain injury treatment and rehabilitation. Firstly, the popular sector of healthcare is cited as the largest and most widely utilized sector within the United States – 70-90% of all sickness is managed within this sphere – and is “the cultural arena in which illness is first defined and health care activities initiated” (Kleinman 2013, 50). This consists of all the non-professional and non-specialist caregivers, including self-care. When it is determined by the popular sector that they can no longer provide adequate treatment, control is often turned over to the professional sector – in Western culture, this is likely modern scientific medicine. Modern allopathic medicine has gained dominance within the U.S. health care field by both “legal and political means” and dictates a substantial amount of social control (Kleinman 2013, 54). This is almost exclusively the first source of treatment that a traumatic brain injury patient will encounter as in most cases the popular sector quickly recognizes their inability to fully treat the condition, and thus is the main comparative focus (to the popular sector) of this paper. The folk sector of healthcare, defined as “non-professional, non-bureaucratic specialist,” will also be occasionally referenced and has played a pivotal role in many TBI patients’ symptom management.

Survey Population

My independently-conducted survey was composed of 25 voluntary respondents from a variety of traumatic brain injury and neurological disorder Facebook support groups. Of the 25, 8

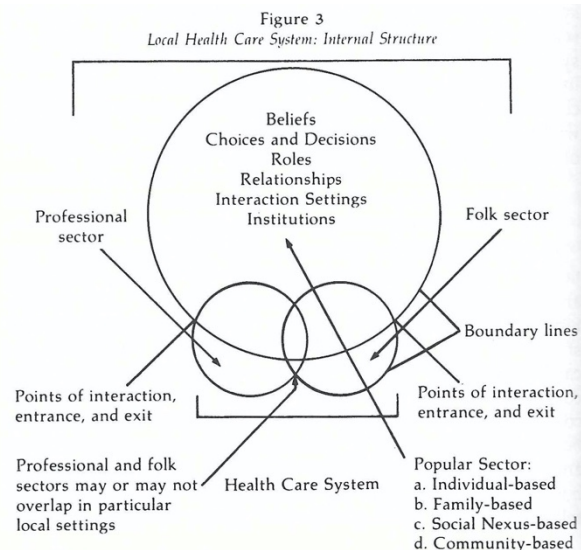


Figure 2: A. Kleinman, *Local Health Care System: Internal Structure*, 2013, in *Patients and Healers in the Context of Culture* (Berkeley: Univ. of California Press, 2013), 50.

respondents identified as a caregiver, 18 identified as a patient/survivor, and 1 identified as a biomedical professional. Of those that responded to the inquiry regarding current residency, 18 participants reside in the United States along with Canada, Iceland, and the Netherlands yielding 1 resident each. 18 respondents have received their primary TBI treatment in the U.S., with 1 respondent receiving care in Canada, 1 in the Netherlands, and 1 in both Iceland and Thailand. All respondents were prompted with the same 31 questions (mix of multiple-choice, checkboxes, short and long answer, and rating scales) and had the option to opt-out of questions at their discretion.

Ethnography

What is the definition of a traumatic brain injury?

In order to obtain a more comprehensive understanding of the TBI experience and how it differs among the lived and professional, the fundamental question of how a traumatic brain injury is defined and contextualized among different groups proved key.

For reference, the Centers for Disease Control and Prevention defines a traumatic brain injury as “a disruption to the normal function of the brain that can be caused by a bump, blow, or jolt to the head, or penetrating head injury” (CDC 2019). This plagues the victim with “a “polypathology” whose main features are white matter degradation, neuronal loss, protein misfolding, and persistent neuroinflammation” (Stocchetti and Zanier 2016, 2). This is accurate as the definition used by scientific medical professionals in the U.S. and is characterized by very specific, technical verbiage. When presented with the task of defining TBI, the slim majority of the survey respondents gave a similar definition based in scientific fact and jargon. However, over 40% of the respondents gave a non-traditional answer rooted in the personal, emotional, or sensory experience of TBI. Some examples include, “never being the same”, “a huge loss”, “a

never-ending fight for my life”, or “A change in the way the brain works. It changes the way you feel and think. You realize it but can’t control it” (Gard 2020).

What does adequate treatment look like?

Because every traumatic brain injury is different, there is not one specific treatment that is generalizable for every patient. Rather, I wanted to see if there were any noticeable differences between occupants of the lived and professional experiences of TBI in regard to what adequate treatment looks like, feels like, and accomplishes to each party. This was the focus of four questions within my survey (applicable to patients and caregivers only):

- How supported do you feel by your medical/care providers? (1-10 scale, 1 indicating “not supported at all” and 10 indicating “supported completely”)
- What are your experiences regarding patient-to-physician/care provider communication? (1-10 scale, 1 indicating “I have had the worst experience with communication from physicians/care providers” and 10 indicating “I have had the best experience with communication from physicians/care providers)
- Do you feel that you have the ability to advocate for yourself in a biomedical environment? (Multiple choice)
- In your opinion, how could the relationship between patients and care providers be improved? Could it? (Long answer format)

Consolidating these data, the majority respondents rated the support they received from medical/care providers as higher than 5 on the scale, indicating some level of majority satisfaction. The remaining rated their relationship lower than 5, thus indicating some level of majority dissatisfaction. It is worthy to note that 25% of respondents rated their support from care providers as a 10 on the scale. As for the second question, 62% of respondents rated their experiences regarding patient to physician/care provider communication as higher than 5, indicating some level of majority satisfaction. The remaining 38% rated their experiences at 5 or below, indicating some level of majority dissatisfaction. Here, it is worth noting that 17% of respondents rated their experiences at a 1, the lowest level of satisfaction measured. When asked

if they feel that they have the ability to advocate for themselves in a biomedical environment, 37.5% of respondents answered “yes”, 41.7% answered “no”, and 12.5% answered, “at times.” Finally, when prompted to elaborate on what could be done to improve the relationship between patients and care providers, 36% of respondents gave an answer pertaining to further education for the care providers regarding TBI itself or the social ramifications of the injury. Also notable is that 30% of respondents alluded to a suggestion of care providers treating the patient as a human being, rather than a diagnosis; as well as a handful of pleas for care providers to “believe the patient’s symptoms” (Gard 2020).

What does it mean to be healed from a traumatic brain injury?

In fostering this final research question, I knew that it would be the most difficult to quantify into a generalizable conclusion; however, it is far too significant to pass over for ease of summation. Thus, I presented my survey participants with these three prompts:

- In your own words, what is healing? (Long answer format)
- In your own words, what does it mean or look like to be healed from a traumatic brain injury? (Long answer format)
- What do you feel is most important in the context of the TBI experience? (Multiple choice; *option 1*: “the patient’s desired practices to achieve healing and their definition of ‘healed’”, or *option 2*: “the medical/care provider’s structure practices to achieve healing and their definition of ‘healed’” (Gard 2020)).

Not surprisingly, the first question yielded many varying responses. Nevertheless, I was able to generalize some responses into a few thought categories. 36% of respondents likened their definition of healing to acceptance of their injury and its accompanying effects; 27% to being able to function at the level (or close to) one was able to before the injury; and 18% to healing the physical injury and improvement of their physical, emotional, and spiritual state of being (“being better than you were yesterday”). Although statistically insignificant, one respondent voiced that healing no longer exists within their self-aspirations. Using the same

quantifying strategy for the second question, 32% of respondents did not believe healing from a traumatic brain injury was possible and/or did not know what it meant or looked like to them. Returning to your former self, being able to function in society, and achieving physical healing each possessed an individual 14% of the respondent's definitions, while 9% of respondents cited "learning to live with it" (Gard 2020). Lastly, 83.3% of respondents said that the patient's desired practices to achieve healing and their definition of healed is more important than the biomedical professional's definition, while the remaining 27.7% indicated the opposite.

Analysis

What is the definition of a traumatic brain injury?

Although members of a collective culture "learn how to identify, react to pain, [and] how to label and communicate dysfunction" in similar ways, there is an obvious distinction here between the lived and professional definitions of TBI (Kleinman 1998, 13). It is easily assumed that professional sector healthcare workers tend to define conditions by their scientific, anatomical significance, as is their job. Likewise, it is understandable that the patient would be more personally and psychologically invested in their definition due to constantly experiencing the consequences of the condition. However, this dichotomy often creates many obstacles for both parties. While the medical professional is working within the professional sector and their biological, physical, and social realities; the TBI patient navigates all three healthcare sectors as well as their biological, physical, social, and psychological realities simultaneously. In addition to not experiencing the condition within the same spheres, the medical professional only engages with the patient's experience for a limited amount of time each day, while the patient engages with it 24/7. Consequently, not only do these factors illicit immense fatigue on the part of the patient, but the professional sector is often viewed as apathetic due to a perceived lack of care

towards the patient. These phenomena between the experienced and the inexperienced are described clearly by neurologist Lisa M. Shulman, “At times, we [are] united against the enormity we faced. At other times illness [is] a rising barrier between us, an alien line where we [find] ourselves on opposite sides, where disease [is] a terrible burden that could not be shared” (Shulman 2018, 6). However, as Kleinman notes, patients have “a need for explanations of their health problems that are personally and socially meaningful and that usually requires that the practitioner explain the illness,” thus creating an inevitable paradox – at the same time that patients have difficulty accepting the professional sector’s perception of their illness, they innately crave an authority figure to tell them what it agitates them to hear, emphasizing the immense amount of social control the biomedical field holds, particularly within Western societies (Kleinman 2013, 356). Therefore, the task becomes finding a satisfactory balance between both the need for authoritative, professionally-sourced guidance and mindful regard to the definition and significance the patient gives their condition.

What does adequate treatment look like?

Within the Western societies and U.S. health system, the body is often considered a “discrete entity, a thing, an “it,” machinelike and objective, separate from thought and emotion,” especially when it comes to treatment (Kleinman 1998, 11). The discord in which this definition creates is best explained by Kleinman’s disease vs. illness paradigm, where disease is defined as an “abnormality in the structure and function of body organs and systems” while illness refers to the “experiences of disvalued changes in states of being and in social function; the human experience of sickness” (Kleinman 1978, 251; Kleinman 1998, 5-6; Kleinman 2013, 363):

Disease and illness are usually not distinguished [by the patient]. Most of the time patients are concerned with symptom relief together with treatment of psychosocial

problems produced by the stress of the illness...Problems in clinical care seem to arise when the practitioner is concerned only with “curing” the disease, and the patient is searching for “healing” the illness (Kleinman 2013, 355-356).

Given the responses from the survey of TBI patients, this philosophy makes much sense. The professional sector of healthcare is systematically trained to ignore illness (the experience of the biological, social, physical, *AND* psychological realities), or the problems that the patient see and readily understand, in order to explicitly focus their attention on the disease (the biological, physical, and lesser of the social realities). In other words, they are “taught to cure, not to care” (Kleinman 2013, 363). Thus, the common respondent solution of “increased education” appears logical and accurate, as I will convey further in my conclusion.

As for the responses regarding care providers not believing the symptoms of their patients, an alternate explanation is needed. For one not familiar with traumatic brain injury, this concept might be difficult to comprehend, as symptoms are typically “standardized “truths” in a local cultural system, inasmuch as the groups’ categories are projected onto the world, then called natural because they are found there” (Kleinman 1998, 10). But for TBI patients and popular sector caregivers, this narrative is far too familiar. Drawing from both my personal experiences and my research surrounding this subject, I feel confident in saying that the brain is widely unknown with respect to meaning, structure, and function. As 20th-century philosopher, Ludwig Wittgenstein writes, “One of the philosophically most dangerous ideas is, curiously, that we think with the head, or in the head. The idea of thinking as a process, in an absolutely closed space, gives it the nature of something occult (Bartra 2014, 109). The brain is an occult being within the West’s social reality, not only because of its biologically authoritative powers but for the sheer reason, despite the perceptually advanced biomedical technology humans have

developed, we do not fully understand it; the professional healthcare sector is working to treat an injury like TBI with a very limited knowledge base to begin with. Then, if a patient presents with atypical symptoms or symptoms that are not medically nor technologically identifiable (again, as is often the case with TBI), the physician is dumbfounded often to the point of accusation. Thus, these results are indicative of a common experience among TBI patients, survivors, and their popular sector caregivers. From my perspective, this plays into the larger power dynamic within clinical medicine. The ideology amongst medical professionals is “to regard their own notions as rational and to consider those of patients, the lay public, and other professional and folk practitioners as irrational and “unscientific”...It is maintained with blind conviction even in the face of evidence to the contrary” (Kleinman 2013, 57). Because the patient is subject to all of the biological, physical, social, and psychological realities; they are seen as unfit and impure to the process of cohesive logic by the professional sector and their observations sit largely ignored; thus continues the cycle of “local systems shared meanings [negotiated] among individuals of unequal power who attempt to persuade others of the intensity of their distress and the need for access to more resources” (Kleinman 1998, 15). As will be addressed further, this undoubtedly calls for a reexamination of the broader healthcare system and the values from which it derives its actions.

What does it mean to be healed from a traumatic brain injury?

Overall, healing is an obtuse, far-reaching, and malleable term. More often than not, healing involves giving meaning to the sickness and how the patient is experiencing it. Although the concept is sometimes strictly reserved for traditional folk or alternative medicine practitioners, it often addresses all four realities that the Western patient is experiencing in a health episode, thus proving to be an important multi-dimensional factor within clinical

biomedicine as well. As said previously, the practitioner is often only trained to “cure” the disease, while the patient is “searching for “healing” of the illness,” so the terms “healing” and “illness” are very much intertwined from an anthropological perspective (Kleinman 2013, 356). Once again, a gap emerges between the expectations of the lived and professional spheres, with the professional sector unable to treat the psychosocial and cultural aspects of the *illness* that of the utmost necessity to achieve overall therapeutic efficacy (Kleinman 2013, 361). As Kleinman effectively lays out:

By reducing healing to the language of biology, the human aspects of healing are removed, leaving behind something that can be expressed in biomedical terms, but can hardly be called healing. Even reducing health to the language of behavior...leaves out the language of experience (Kleinman 364).

In the context of traumatic brain injury, this concept of healing fills in this gap in regard to TBI patients’ frustrations with the professional healthcare sector. Neurologist Lisa Shulman writes that “The traumatic nature of events lies in their personal meaning,” which is inarguably true in the case of a TBI patient (Shulman 2018, 86). In varying capacities; personhood, independence, and identity are lost for the victim; yet this is seldom addressed by any member of the medical team whose jobs it is to create a positive reality for the patient post-injury. The furthered integration of healing into the biomedical world would be simple; all the medical professionals would have to do is redirect and redistribute their mental efforts to include treatment of illness and recognition of personhood. From the professional sector’s perspective:

The metaphor of a wounded mind and brain makes sense. We understand the concept of wound healing. The healing process goes through stages that may be shorter or longer in different people. When medical doctors assess the healing process of a physical wound,

our main focus is whether healing is continuing...But when the wound gradually improved – understandably slowly in some circumstances – and the person gradually regains function, we perceive this as part of the natural healing process” (Shulman 2018, 89).

If we can apply this biological process to understand the personal healing process, many of the destructive patient-to-professional interactions would be eliminated. Once again in the eloquent words of Kleinman, “by freeing ourselves from ethnocentric and “medicocentric” views, we may begin to recognize important issues that thus far have been systematically ignored” (Kleinman 1978, 251).

Reflection on Methods

All in all, my research for this paper was immensely broad and managed to encapsulate many diverse experiences into a single, collective narrative. However, there are some pertinent discontinuities within my research that are crucial to recognize. Firstly, the independently-conducted survey for this study focused on just 25 individual responses: a very quantitatively-limited dataset that is difficult to generalize for an entire population (of TBI associates). It is also important to note that these data were collected from an online support group, thus implying that they have struggles for which they are looking for support from others to cope with. Generally speaking, this makes it more likely that the survey population had more extensive struggles/were more vocal about their struggles in their TBI experience, thus making it more likely to garner negative responses, particularly towards healthcare professionals. In addition, this limited data included only one direct professional healthcare sector perspective. The COVID-19 pandemic severely interrupted my research in this regard, as I was planning on gaining more biomedical perspectives through in-person interviews, most of which could no longer be carried out because

of social distancing guidelines and scheduling conflicts. I also planned on attending an in-person support group to collect perspectives, but COVID-19 allowed for this neither. As a final note, this research did not touch on the issues of stigma and identity; both of which are important topics to consider when conceptualizing the TBI experience. Just as anthropology is a broad field that encompasses many different typologies, there are many different tools in which anthropologists use within their fieldwork and to craft their overall research argument. While I was not able to employ many of these, there is a substantial need for unique and relevant studies that utilize not only interview and survey; but observation, longitudinal studies, etc. Each of these allows research to flourish from a different angle, making for a more complete contribution to human thought, behavior, interaction, sociality, and culture.

Conclusion and Future Directions

Throughout this research, many issues arose within the social reality of traumatic brain injury treatment and rehabilitation, particularly amidst the TBI patient and the professional healthcare sector. Despite the variability in relationship and incidence, the remaining need for a more empathetic, understanding of clinical reality is paramount to the continued improvement of the TBI experience.

In a 2000 study done by Dr. Grahame Simpson assessing the cultural variations and values of TBI and TBI rehabilitation, his team found that the qualities of attentiveness, friendliness, and guidance among healthcare professionals were the most valued by the TBI patient (Simpson 2000, 125). Given this, there exist three models authored by Arthur Kleinman that have the potential to implement these characteristics within the professional healthcare sector. Firstly, the negotiation of shared models is a framework to help clinicians “mediate between different cognitive and value orientations” and is framed as a “therapeutic ally” who

negotiates with the patient about treatment. This is model touts the potential to not only gain the patient's trust but provides a simple guide to accessing the "impact of social and cultural factors on the illness, the patient, and the family" (Kleinman 1978, 257). Additionally, clinical social science presents a viable educational opportunity in medical schools and teaching hospitals. Although many of these measures have been implemented in major health systems in recent years (e.g. clinical social workers), this model proposes physicians be trained in anthropology or sociology in order to assist the hospital to better navigate patient realities and be more sensitive to the vulnerable position of the patient overall (Kleinman 1978, 257). Finally, the concept of interpretation of illness meanings shows promise in encouraging more effective and meaningful care to patients. As cited by Kleinman, this mental model reimagines the professional healthcare sector, urging medical professionals to reconceptualize "medical care as (1) empathetic witnessing of the existential experience of suffering and (2) practical coping with the major psychosocial crises that constitute the menacing chronicity of that experience" (Kleinman 1988, 10). The overarching goal for this concept is to "liberate sufferers and practitioners from the oppressive iron cage imposed by a too intensely morbid preoccupation with painful bodily processes and a too technically narrow and therefore dehumanizing visions of treatment" (Kleinman 1988, 9). In addition to these frameworks, I would personally recommend increased collaboration between the professional healthcare sector and the folk sector (traditional folk/indigenous practitioners). As is recognized by many esteemed sources in medical anthropology, these personnel "seem to be remarkably skilled at giving meaning to the experience of illness and, through that and other means, producing a behavioral and experiential impact, whether they change symptoms or not" (Kleinman 2013, 356). This move could open up

a wealth of opportunities for both fields; but most importantly, for the increased wellbeing of the patient.

From this limited research study and the various literature sources aiding in its analysis, it is unquestionable clear that traumatic brain injury patients experience and struggle through this incredibly complex and dehumanizing diagnosis; in part due to the lack of cooperation, understanding, empathy, and recognition they are receiving from the professional healthcare sector throughout their treatment and rehabilitation journey. In the words of Kleinman, this “calls for a fundamental reconceptualization of clinical care and structuring of clinical practice. If appropriately trained, the modern health professional can effectively and systematically treat both disease and illness” (Kleinman 2013, 363). Although the end is hardly in sight, it is of the utmost importance that we continue to build narratives that support the traumatic brain injury experience. Every TBI is different, but it is only through the universalities and shared struggles of this condition that we will achieve solutions.

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