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## **Cultural Perceptions of Traumatic Brain Injury and Rehabilitation in Minorities**

Lyanna Díaz

*Paula Rodriguez is a 33 year old Hispanic woman who grew up within a very traditional Hispanic culture. She sustained a traumatic brain injury (TBI) after being involved in a front end car collision. Paula was in a coma for a week and when she awoke she was extremely disoriented and confused. Doctors wanted Paula to start the rehabilitation process as soon as possible so that she could begin living independently again. Paula, however, believes that her TBI is from God and that it was fate that she sustained her brain injury; therefore she doesn't want to go through rehabilitation. Since Paula grew up within the Hispanic culture, religion has played a crucial role in shaping and guiding her views and ways of living. Another factor contributing to Paula's decision about rehabilitation is her dependence on her "familia" or "family unit". Within the Hispanic culture, the family unit includes more than just immediate parents and children; it also includes the entire extended family. It is expected that all individuals of a family have a moral responsibility to help other members of the family when they are experiencing any kind of trouble, including poor health conditions. For this reason, family ties are very strong and there is an extreme amount of value placed on the opinions of family members, especially the elderly generation because of their life experience. Therefore, instead of trusting in the healthcare professionals for treatment, Paula relies on the advice of her family who believe that prayer and "curanderos", or holistic spiritual healers who offer simple home remedies, would be better qualified to treat Paula's disability.*

Traumatic Brain Injury, or TBI, is damage to brain tissue caused by an external mechanical force and can cause cognitive, behavioral, emotional, and social problems [1,2]. It is a major cause of death and disability among young adults in the U.S. Around 1.4 million head injuries occur every year and an estimated 5.3 million Americans (~2 % of the population) are living with lasting impairments due to TBI. The major causes of TBI are falls, motor vehicle collisions, and violence [1]. Yet despite these high occurrence rates, very few studies specifically address traumatic brain injury and even fewer take into consideration the growing minority population and their specific cultural backgrounds [3].

The minority population is growing rapidly and will constitute about 45% of the country's total population in the year 2050. As of 2007, there are higher reported incidences of TBI among Hispanic/Latinos and African Americans than for Caucasians [1]. Even so, there is still very little known about the relationship between minority status, TBI, and rehabilitation outcomes [1,4]. Due to the rising incidence of TBI in minorities, there is a growing need to examine differences in the ways that minorities and other cultures perceive illness and the expectations they have of physicians—especially in terms of TBI rehabilitation methods.

The above case study shows an example of how culture can and will impact both perception of a traumatic brain injury and the rehabilitation process. People from different cultures have unique expectations of what it means to be ill or to have a disability. For example, Paula from the case study would probably expect to be

pampered during her disability treatment because this is one of the ways that her family shows they love her and are concerned. For the purpose of this paper, disability will be defined as what happens when a person with an impaired organ attempts to engage in his or her world [5]. Different minorities and their cultures also have different expectations of how they should be treated for their illness and what they expect from the professionals treating them. Becoming aware of the differences in minorities and cultures will allow for a better rehabilitation process in the long term [4]. The purpose of this paper is to explore the issues and challenges associated with a traumatic brain injury, and to take a deeper look at the issues that arise when minorities are dealing with this serious disability, particularly in terms of the rehabilitation process and cultural competency of healthcare providers.

### **Challenges with TBI and goals for rehabilitation**

Just like people, no traumatic brain injury is the same as another. The severity of the brain injury can range from mild to moderate to severe and can affect many areas of a patient's life including cognition, social behavior, and physical functions. Depending on the severity, injuries can last a lifetime or may heal over a relatively short period of time [6].

The main purpose of rehabilitation after a traumatic brain injury is to try to restore the parts of life that have been affected by a brain injury. This involves letting the body heal, re-learning any skills that may have been lost, and learning new ways to accomplish goals. Ideally after rehabilitation the patient will be able to live relatively independently. However, the goal of living an independent life is a Westernized ideal and might not be the end goal of minorities from other cultural backgrounds. In fact, culture affects many different areas of how minorities react to injuries and what they, as patients, expect from medical professionals when being treated for their injuries. The next sections provide examples of the ways in which different cultures perceive illness and disability and what patients from different cultures expect when receiving treatment for their illness.

### **Cultural effects in the perception of pain and illness**

According to Banja (1996), culture is a collection of beliefs, habits, and practices that serve three functions... to determine our social relationships ... to assist individuals to explain life or reality ... and to serve to differentiate one social group from another social group. Culture can alternatively refer to groups of people based on ethnicity, gender, religion, sexual orientation and social class. Cultural norms outline values by guiding beliefs, choosing what is considered healthy, showing how physical symptoms should be interpreted and expressed, and showing the expected outcomes of illness or disability [7].

In Western culture, causes of disease or disability are generally based only on biology [5]. However, many other minority cultures, such as the Chinese culture, would not even consider biology as the cause and would explain disease as an imbalance of the body's hot and cold systems. Still other cultures would explain disease as having lost one's soul, or that their disability is the result of a hex which is why they tend to seek help from spiritual healers [5]. From these examples, it can be seen that there are

many ways to interpret various diseases and disabilities and that the interpretation is entirely dependent on culture.

### **Culture determines a patient's expectations and interactions towards physicians**

According to Simpson et al. [8], every cross-cultural physician relationship interacts with four different cultures: the culture of the physician, the culture of the patient, the culture of the medical system the physician is operating under, and the patient's traditional medical culture. Due to these four different cultures, many forms of communication can be hindered, such as body language and actual differences in language spoken.

An example of differences in the culture of the service provider and culture of the patient can be illustrated with a physician-patient interaction involving the Native American culture. Customarily in the Native American culture, it is considered rude to make direct eye contact with other people. If a Native American person were to visit a Western physician, he would most likely make an effort to not look at the physician in order to be respectful [5]. This doesn't seem like a practice that would cause much confusion, but in Western culture, eye contact is extremely important for effective communication. If two people were conversing and one person wasn't making eye contact, interest and effective communication in the conversation would quickly be lost. When there is lack of eye contact, one could think that the other person isn't listening or can't hear what he or she is saying. In Western culture, several ideas are conveyed through eye contact, including appreciation, understanding, potential interest, and the deliberate attempt to make or solidify a friendship [9]. Therefore, the Western physician, if not knowledgeable about Native American customs, could interpret lack of eye contact as indifference, resistance, or disinterest. The physician may then try to force eye contact, but this tactic would likely make the patient feel uncomfortable, which would only hinder the entire diagnosis and treatment process [5].

### **Misconceptions about TBI**

Education about traumatic brain injury is extremely important, especially within minorities of different cultures. Pappadis et al. (2011) conducted a study to find out the extent to which TBI is misunderstood and if different minorities vary in the extent that they misunderstand TBI. They found that between African Americans, English-speaking Hispanics and Spanish-speaking Hispanics with TBI, there was an overall difference in the percentage of misconceptions about their illness, purely based on which language they spoke. This significant result was found after the researchers controlled for education level, religious participation and socioeconomic status. Most significantly, Spanish-speaking Hispanic people with traumatic brain injuries were more likely to hold the most misconceptions because they had a different primary language than that of their healthcare providers.

If patients with traumatic brain injury have misconceptions about their illness, they might try to set unrealistic goals for themselves. Due to these unrealistic goals, they may become disappointed during the rehabilitation process if their progress doesn't match up with what they expect. In the long run, this unrealistic goal setting could be detrimental to the recovery process if patients don't make the progress they are expecting, they may lose interest in continuing rehabilitation as they think it is not

helping [10, 11]. Therefore, in order to get the best outcome in rehabilitation treatments with minorities, one of the first steps is to make sure that the patient understands as much as possible about his or her illness and limitations; that way, when rehabilitation is occurring, realistic goals can be set and progress for that particular individual can match their expectations.

### **Goals of rehabilitation**

Most cultures have different ideas of what being ill or disabled means, so it is likely that rehabilitation is going to look different depending on cultural background. In the country of Bhutan, physicians may use the same physiological measures that Westerners use to assess illness or disability, such as pulse rate; however, for the Bhutanese, pulse is not intended to measure the rate of blood flow but rather the proportion of air, bile, and phlegm that is in the patient's body. However, this practice would not be used in Western culture and could cause conflict between healthcare providers and patients.

Rehabilitation is generally defined as a treatment process designed to facilitate the process of recovery from injury, illness, or disease to as normal a condition as possible so that the patient can be a functioning member of society [12]. However, this may not be the end goal for all patients. For example, in Hispanic cultures, family members are much more dependent on each other than in Western culture so a TBI patient with a Hispanic cultural background will probably not desire to become as functionally independent as someone with a Western culture because the Hispanic person has family members to rely on.

### **Family involvement in rehabilitation**

Family involvement is an extremely important part of rehabilitation. Cavallo and Saucedo (1995) found that there are many cultures where family is much more involved than in Western culture. It was even found that extended family members often contribute greatly. For example, in Hispanic families, it is more likely that extended family, such as in-laws, would help in the protection and care of a person with TBI than in other cultures.

Relatives carry a great deal of the burden when caring for their TBI relatives. It is a very stressful and difficult job for family members to have to take care of their relatives who previously could take care of themselves. Watanabe et al. (2001) study showed that families who were able to accept a patient's disability and adjust the work load to effectively help with the rehabilitation process could positively affect rehabilitation outcomes in TBI patients. The opposite is true as well; if the family cannot accept a patient's disability and cannot re-adjust the work load, then their stress may negatively influence the rehabilitation outcome of the TBI patient [13].

There are so many factors that contribute to whether or not someone with a traumatic brain injury will be successful in their rehabilitation. All of these factors, though, stem from one place: the culture in which the patient was raised. From expectations of what rehabilitation will do for them, to family involvement in the recovery process, minority TBI patients have a lot of factors stacked against them. If medical professionals can become aware and more sensitive to cultural differences of their

patients, then the rehabilitation process for each individual will greatly improve. This is the ultimate goal.

## Application

Considering all the issues surrounding effective rehabilitation with different cultures, it seems like the natural next step would be to educate those who are currently training to work in the medical field, such as occupational or physical therapists, and interact with patients on a daily basis, to be more sensitive and aware of those cultural differences. In talking to an occupational therapist, I discovered that she had never been taught to be sensitive towards cultural differences, but rather, it was a skill she had to develop for herself. Through many angry or unsatisfied patients and families, and even from being fired, this occupational therapist had to learn the hard way how to read her patients and ask the right questions in order to get to the essence of what is most important to the patient. Not every patient is going to have the same goals for themselves as the occupational therapist does, which can cause contention and even hinder the rehabilitation process. For this reason I made a website discussing the current issues in providing rehabilitation and ways to potentially increase awareness of cultural differences and work effectively with minorities of differing backgrounds.

In essence, the next step is for healthcare providers to begin actively working on their cultural competency, or their ability to interact effectively with people of different cultural and minority backgrounds. If even basic skills of cultural competency can be achieved then patients and healthcare providers will be able to work together more effectively to come to a common ground where patients feel their expectations are being met and respected and where healthcare professionals are able to provide the best treatment options possible.

The screenshot shows a website with a dark green header and a light green sidebar. The main content area is white. The header contains the title 'Cultural Perceptions of TBI and Rehabilitation' and a search bar. The sidebar lists navigation links: Home, Contacts, Project Documents, Media, Seminar, and Sitemap. The main content area features a section titled 'Overview' with a horizontal line below it. The text under 'Overview' discusses Traumatic Brain Injury (TBI) and its prevalence among different ethnic groups. To the right of the text is a blue-tinted image of a human skull. Below the 'Overview' section is another section titled 'Objectives' with a horizontal line below it. The text under 'Objectives' states that rehabilitation needs to be individualized and dependent on cultural background and patient values.

<https://sites.google.com/site/culturetbiandrehab/>

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