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Soy Diferente: A Qualitative Study on the Perceptions of Recovery Following Traumatic Brain Injury Among Spanish-speaking US Immigrants

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Abstract

Purpose: To explore the impact of traumatic brain injury (TBI) on the quality of life (QoL) and self-concept of Spanish-speaking US Hispanic immigrants with TBI.

Materials and methods: A prospective, qualitative study conducted in a county level I trauma center and community. Semi-structured interviews on QoL and self-concept following TBI were conducted with twenty-four Spanish-speaking US Hispanic immigrants with TBI living in the community at least 6 months following injury.

Results: Perceived facilitators of QoL included faith, hopefulness in recovery, empathy for others, and support from others. Perceived barriers to QoL mentioned were symptoms/consequences of injury, employment/financial changes, loss of independence, fear/uncertainty, stigma/shame, lack of medical care, and decreased social integration. Participants described their self-concept after TBI as either a maintained self or loss of self. Those who viewed themselves differently reported physical and emotional changes, gender role conflict, loss of self-worth, and total loss due to the TBI.

Conclusions: Spanish-speaking US Hispanic immigrants held a strong faith and positive outlook after TBI in spite of the significant barriers to recovery. A need exists for programs to support creatively the recovery of Spanish-speaking US Hispanic immigrants with limited access to care and resources.

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Keywords

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Introduction

Hispanics are the largest US ethnic minority group, making up 18.3% of the total population [1]. They are disproportionately represented among persons with traumatic brain injury (TBI) [2]. Unfortunately, Hispanics with TBI have poorer outcomes compared to Non-Hispanic Whites (NHW) in the areas of employment and other productive activities [3, 4]. Racial/ethnic minorities, specifically Hispanics, report poorer functional outcomes, less access to rehabilitation services, decreased employment or productive activity, and poorer community integration following TBI compared to NHW [5, 6, 7].

Access to care, particularly for immigrants, presents significant challenges.[8] Compared to NHW, Hispanics with TBI report longer wait times to see an emergency room physician [9]. They are also more likely to be discharged home and less likely to receive rehabilitation services following acute hospitalization [10, 11], and have worse functional outcomes at one-year post injury [12]. Ethnic disparities in outcomes following TBI may be partially explained by insurance status [4]. Uninsured Hispanics with TBI are at greater risk for mortality compared to uninsured African Americans and insured Non-Hispanic whites with TBI [13]. Whether privately insured, publically insured, or uninsured, Hispanics have a lower rate of receiving post-acute care following hospitalization [14]. Primary language is a potential contributor to disparities in health care access and outcomes for Hispanics with TBI. Over seventy percent of Hispanics in the United States speak Spanish at home [15].

In the U.S., there are an estimated 10.5 million undocumented immigrants, of which 73% are from Latin America. The majority reside in California, Texas, Florida, New York, New Jersey and Illinois. Undocumented immigrants from Mexico and other parts of Latin America reported having less health care access, less use of healthcare services (i.e., physician visits) and poorer care encounters compared to US-born Mexicans and other US-born Latin Americans [16]. Undocumented immigrants in the US are treated at nonprofit safety net hospitals that receive public funding and are legally required to provide care regardless of insurance status or ability to pay [17]. Under the passage of the Patient Protection and Affordable Care Act (ACA), which passed in 2010, undocumented immigrants are not eligible for health insurance for catastrophic illnesses, including traumatic brain injuries, causing an ongoing national debate over medical care access [18]. Under the current U.S.administration, proposed policy changes may cause even greater health care disparities among undocumented immigrants in the US, especially in Texas [19].

Few studies have examined the needs, barriers, outcomes, and experiences of Spanish-speaking persons with TBI in the United States [20]. Spanish-speaking individuals with TBI experience unique challenges and report long-term functional impairments [21], such as barriers to service utilization, lack of financial/medical resources, lack of language services, and difficulties with activities of daily living. The proportion of foreign language speakers

in the neighborhood has been shown to moderate the relationship between nativity (US born or immigrant) and productive activity at one-year post TBI [22]. Furthermore, persons with TBI in the U.S. who are non-US born and Spanish-speaking are more likely to report greater misconceptions about TBI than those who are not [23]. The challenges faced by Spanish-speaking Hispanics with TBI have the potential to negatively affect quality of life (QoL) and self-concept.

A number of studies have explored QoL and self-concept following TBI [24, 25, 26, 27]. During and after the first year, individuals with TBI report a decrease in health-related QoL. In addition, they generally report negative changes to their self-concept or sense of self, which is also related to emotional distress and lower subjective QoL. In over 40 years, there has been a paucity of studies exploring the lived experience of ethnic minorities with TBI [28]. In the existing studies, some recurring themes include a disconnection with self and others, unresolved emotional sequelae, internal and external resources to support recovery, and the reconstruction of self-identity. However, no study has qualitatively explored the unique perceptions of QoL and self-concept in the recovery of Spanish-speaking persons with TBI in the U.S. Therefore, this study aimed to investigate the unique experiences of non-US born Spanish-speaking persons with TBI, who are living in the U.S. Specifically, we explored their perspectives of the impact of TBI on their QoL and self-concept at least 6 months following injury.

Methods

Participants

Spanish-speaking persons with medically documented TBI were recruited based on their consecutive admission to the Neurosurgery Intensive Care Unit of a large county Level I trauma center. Participants were part of a larger study assessing racial/ethnic diversity in community integration among persons with TBI. Participants for the larger study had to meet the following eligibility criteria: medical documentation of mild, moderate, or severe TBI; age \geq 18 years; English- or Spanish-speaking; discharge to a private residence following either acute care or inpatient rehabilitation; at least 3 months living in their community; at least 6 months post injury to ensure that participants have attempted to integrate back into their community; and absence of any pre-existing severe neurological (e.g., stroke, Parkinson's disease), psychiatric (e.g., bipolar, schizophrenia), or developmental and intellectual disabilities (e.g., autism) that could impact community integration irrespective of TBI. However, only transcripts from the non-US born, Spanish-speaking persons with TBI will be addressed in this study. The Institutional Review Board of Baylor College of Medicine and Affiliated Hospitals approved this study.

Procedures

Potential participants were invited to participate in the study by phone and/or mail. Informed written consent, a semi-structured interview, and assessment measures were conducted in each participant's home at approximately 6 months after injury (Mean=9.25; SD=4.64, range= 6-21) by the first author, who is bilingual in English and Spanish. All audio-recorded interviews were conducted in Spanish by the first author (MRP), and were later transcribed

into Spanish using a professional transcription service. The semi-structured interview questions assessed participants' perception of the impact of the TBI on their QoL and self-concept. The main interview questions were: (1) "How has the brain injury affected the overall quality of your life?"; (2a) "How has the brain injury affected the way you see yourself?"; and (2b) "Do you see yourself as the same as before your injury or different?"

Qualitative Data Analysis

Two independent research team members (MRP and DKM) who are fluent in Spanish independently coded all interviews. Qualitative data analysis was based on the multi-step coding process of grounded theory [29]. Coding involved reading the transcript in Spanish line-by-line several times and then identifying key words or statements using direct responses from the participants. Independently generated themes of the two coders were compared for consistency and then core themes were identified. Coders then discussed any coding discrepancies until consensus was achieved. Codes and the data used to identify the codes from the participants' responses were back-translated into English for reporting and checking accuracy. All authors reviewed and confirmed the codes. We created a respondent-by-theme matrix to explore theme patterns and guide the constant comparative analysis [30]. The analysis was conducted using the qualitative analysis software NVivo 10 [31]. Excerpts from the data were selected to illustrate the final core themes identified. Embedded in the description of the results are direct quotes or statements by the participants, which are denoted in italics. The study results are reported following the Consolidated Criteria for Reporting Qualitative Research (COREQ) reporting guidelines.

To ensure rigor and trustworthiness of the data[32], we used the following strategies. The interviewer established rapport with the participants and, in some cases with family members, early following injury while the participant was hospitalized in the acute hospital. The interviewer then maintained contact until the former patients had been living in the community for at least six months, which is a slight variation from prolonged engagement. For investigator triangulation, two coders were used for the data analysis, and the research team provided feedback on the coding decisions. To ensure transferability, we provided thick descriptions of the participants' experiences by including contextual information with the quotes. Lastly, we documented our research procedures and code development, as well as provided the exemplar quotes in both English and Spanish (See Supplemental material) to ensure dependability and confirmability of the results.

Results

Twenty-four individuals who self-identified as Hispanic and indicated that Spanish was their primary language were recruited and participated in the qualitative interview (table 1). Just over half of the participants had a medically documented mild TBI (best 24-hour Glasgow Coma (GCS) score: 13 to 15), while the remainder sustained moderate-to-severe TBI (GCS score: 3 to 12) [33]. Best 24-hour GCS score is the preferred GCS score in neurotrauma research, as the GCS score is confounded by lesion removal, anesthesia, sedation, or alcohol [34, 35, 36]. Seventy-nine percent were male, and 79% had less than a high school education. The mean age of the participants was 38.2 years ($SD=16.9$). Half

of the participants had lived in the United States for five years or less. The participants emigrated from various Latin American countries, including Mexico, El Salvador, Honduras, and Guatemala. Participants largely self-identified as Catholic and as actively practicing their religion. The majority (83.3%) were employed pre-injury, but only 38% were employed at the time of assessment. Sixty-five percent of participants reported annual household incomes of less than \$20,000, and had an average of 3.9 people residing in the home ($SD=1.6$). The etiologies of injury were motor vehicle or motorcycle accident ($n=8$), assault ($n=7$), fall/jump ($n=4$), auto-pedestrian ($n=3$), gunshot wound ($n=1$), and being hit by an object ($n=1$).

Metacoding, the examination of the relationships among themes, resulted in identifying overarching metathemes [30]. We consolidated the inductively derived codes into themes, and then aggregated the major themes into larger metathemes. Two metathemes, driven by the study questions and four emerged themes, were identified: QoL and Self Concept. The four emerged themes were: (1) Facilitators of QoL, (2) Barriers to QoL, (3) Maintained Self, and (4) Loss of Self. Figure 1 is a visual representation of the thematic network that summarizes the study results [37]. The participants perceived the traumatic brain injury to have a positive or negative influence on both their quality of life and self-concept following injury. Table 2 includes the metathemes, categories, and examples of the codes identified inductively. Direct quotes in Spanish and English are available in the Supplemental Tables 1 and 2.

QUALITY OF LIFE

The majority of participants ($n=18$, 75%) felt that the TBI affected their overall QoL. Some of the effects were perceived as positive, such as no longer using drugs or alcohol, or attaching increased value to life. Others were perceived as negative, such as not being able to do pre-injury activities, inability to work, loss of sense of smell and taste, and feelings that the TBI completely changed their life. The remaining 25% of participants perceived no impact of the TBI on their QoL. These participants described themselves as feeling *normal*, and not experiencing changes in *work* or *communication with family*, and that they *think the same* as before their injury. Most of those who did not believe that the TBI affected their QoL still identified changes, such as *being careful*, *fear and anxiety* that is getting better with time, having physical changes (*scars*), and *going to church more*.

Supplemental Table 1 provides illustrative quotations for the themes and subthemes for the QoL meta-theme. No theme pattern differences in perspectives of QoL were noticed based on years in the United States (< 5 years vs. >5 years) or injury severity (mild vs. moderate-to-severe) after reviewing a respondent-by theme matrix.

Facilitators of Quality of Life

Faith—Nearly all participants were of Catholic faith and actively practicing their religion. They described being thankful to God for being their *source of recovery*, giving them *the license to continue living*, providing another opportunity for their family to see them alive, and *showing His favor*. Many talked about the role God plays in their life and recovery, such as placing God's authority before medical doctors, and returning them to normalcy by

feeling like a *normal person and 100%*. They had an overwhelming sense of gratitude for life and recognition of God’s role in their recovery and the prevention of potentially worse outcomes following the TBI.

“But, thanks to my Lord who lifts me up. I know that one day, my Father will give things again so that I be who I was before. In addition, with the Lord, I feel very different, very happy. Because I do believe in Him. Faith – I never accepted and I know that one day...He will lift me up, slowly, but He will lift me up.”

(P161, male, severe TBI, 11 months post)

Hopefulness in Recovery—Recovery was described frequently in terms of percentage, such as 85-90%. Participants described the importance of being optimistic or hopeful in their recovery after the TBI. They described their resiliency by being able to *move forward with life* after injury. It was mentioned frequently that, with time, symptoms will get better and circumstances will improve. A participant described his perception that there will always be problems, but that focusing on the positive is necessary for improvement: “*we have been given a second opportunity to continue living.*” (P343, male, mild TBI, 21 months post).

Some participants described that the injury led them to place greater value on life because they realized that it is vulnerable to loss. Others described their attempts to de-emphasize the injury itself, as they adapt to injury-related changes, which they perceive as a *process*.

One participant viewed their experience positively as a success:

“I feel good, what they have done to me in the hospital, everything has been successful and will always be...will continue to be that way.” (P575, male, severe TBI, 7 months post)

Empathy for others—Some participants reported that they gained a new empathy for individuals with disabilities, as they understood the resulting pain and loss. One participant desired that others be as well as he, as he saw himself recuperated (P481, male, moderate TBI, 10 months post). In contrast, not all participants viewed themselves as recovered. A Salvadorian woman with children not living in the United States felt *immobilized* because she wanted to help others who were suffering from a recent hurricane but felt useless, mostly because of the barrier of not speaking English. She described experiencing many catastrophes and wars in her home country and once being *courageous, but now feeling spiritless* (P217, female, mild TBI, 6 months post). The TBI and inability to speak English made her feel useless to others and she was no longer in the financial position to return to her home country.

The participants have placed greater importance on their lives, which gave them a greater understanding of the experiences of others with TBI:

“We give life and things more importance. Everything around us ...and to better understand the pain of others. Because we already lived it.” (P343, male, mild TBI, 21 months post)

Support from others—Due to the cognitive and physical limitations following their injury, many received or continued to receive *support from their family or friends* throughout the recovery process. None of the participants had medical insurance and they relied on county resources for their medical care. One participant detailed how he needed help for everything except eating. He joined a support group with other men with brain injury from Mexico because none of them receives assistance outside of the support group:

“I’m in a group of people with disabilities, and we support each other. All Mexican and we don’t receive any help. We do everything for each other. That’s how we all move forward.” (P261, male, moderate TBI, 19 months post)

Barriers to Quality of Life

Symptoms or Consequences of Injury—Symptoms explored behavioral, cognitive, emotional, personality, and physical changes common following TBI. The vast majority of participants experienced physical changes, such as body image changes, decreased movement or mobility, dizziness, new onset of a seizure disorder, fatigue and sensory/perceptual impairments (i.e., vision, taste, smell, hearing, visuospatial). Many stated that the physical changes affected their ability to return to work following their injury. Another participant described how in the past he could run so fast that immigration officers could not catch him. After his injury, he always feels as if he is going to fall if he runs, and knows that now they would be able to catch him.

Cognitive changes, such as decreased memory and concentration, affected their QoL. One participant from Honduras shared several stories of losing things or money due to memory problems. For example, he was at the store and forgot that he put his wallet down. Once he remembered and returned, *someone emptied out the money* (P507, male, mild TBI, 6 months post). Memory changes was the most frequently mentioned cognitive change.

“Memory. That’s where I think it most affected me. Because I do one thing or I am in a place and awhile later I don’t remember what I did or where I was. That’s where I believe I was most affected.”

(P150, male, moderate TBI, 11 months post)

Common psychological changes following injury included emotional distress, decreased mood, anger, and aggression. A participant reported the inability to control his behavior, *disinhibition*, particularly with making decisions, which negatively affected his QoL leading to uncertainty about the future (P154, male, moderate TBI, 7 months post). One participant hoped to recover physically and emotionally in order to have a normal life, and although she has sought psychological help, she still feels the same:

I’m just at home thinking about the accident, the failures, pure negative things, so I think that fills my heart with bad emotions and that’s not good for a normal life. I think my thoughts are going to focus on what I am living and not on what has already happened. (P130, female, severe TBI, 8 months post)

Employment/Financial Changes—As non-US born Spanish speakers, inability to work caused significant financial struggles for many. Only nine of the participants maintained

employment following their injury. One female from Mexico decided to go to college following her injury, while another maintained her role as a homemaker. The remaining participants lost their ability to work and had not returned to work by 6-months post injury. They reported significant financial challenges, which resulted in emotional distress.

“My economic situation...is what I feel bad about...it changed my entire life.”
(P605, male, mild TBI, 6 months post)

Through tears, a mother, living apart from her children, described how her finances changed due to her inability to work.

I did not come here for luxuries, but to send money to my children so they can study and to save something. Why? So that I can return to them. And, what happened? I had to spend the money. Because the savings I had been saving was spent...because of not working all of this time without a job or anything. And, I had to study. I had to eat. (P217, female, mild TBI, 6 months post).

Those who were able to return to work experienced *more pressure, decreased patience from others, made errors, or could do only half of what was done before*. When a participant was asked if others notice his changes at work, he said, “*Yes. But what are they going to say now? Errors are like that. One day it’s one and tomorrow it’s another.*” His memory problems caused him to make errors, which were noticed by others. He wanted them to have patience with him but they would still pressure him to work.

Loss of Independence—Many perceived a loss of independence related to injury-associated financial challenges, physical limitations, or housing changes. They described being able to do as they pleased before, but now being *limited, dependent, or needing assistance from others*. One participant lost his vision following the TBI, and desired to do things like before, such as working and going out. It bothered him to have to depend on government assistance and rely on others for housing.

One participant was completely independent before her injury, but following the injury she struggles with the fact that now she has to depend on others:

“I used to do my things, I fixed my suitcase, I went out, I went in, I went, I came, I was independent and now I don’t...It’s serious because now I depend [on others].”
(P335, female, mild TBI, 20 months post)

Fear/Uncertainty—Some participants shared fears with which they were dealing, such as fear about *getting another TBI, getting lost, and doing things that will harm them*. One individual described his desire to return to his home country due to the difficulties experienced in the United States following his injury. Some questioned their future goals and plans, or why they came to the United States in the first place. These thoughts were associated with increased stress.

“I have to be very careful not to injury myself...the injury could be worsened.”
(P611, male, mild TBI, 6 months post)

Stigma and Shame—Some described a stigma associated with having a TBI. They perceived others as treating them differently, resulting in feelings of shame. Many experienced shame *walking in their neighborhood*, where *people see* them, and *refused to go to the store due to shame*. There was concern for how others perceived them or concern that others would laugh at them for not being able to do the things done before. For one male, the belief that no one thought he was efficient or saying, “*no one needs me*,” negatively affected his life after injury. A participant, who stayed indoors due to feelings of shame, described her injury due to a car collision as, “*it completely changed my life from one day to the next*.” (P130, female, severe TBI, 8 months post)

Lack of Medical Care—Medical care, such as needed surgeries or bone flap replacements, was often difficult to access. Some perceived that they could not rely on their physicians once they returned to the community because of the challenges with accessing health care. A female participant described her experiences with wanting to talk to someone about her problems, but not wanting to *talk to a therapist or social worker and share her feelings with someone that doesn't care and only listen*. Just 6 months post injury, one male participant described experiencing delay in care, “They have to first attend to the emergencies....my operation that they are going to do can wait one year, two or more years. Now they are leaving me like this.” Immigration status plays a role in the ability to access and obtain health care.

Care is often delayed for undocumented immigrants, which affects how they perceive their recovery:

“I need another surgery and I'm not 100%. But if I had another surgery, I would already feel 100%.” (P575, male, severe TBI, 7 months post)

Decreased Social Integration—Individuals reported changes in their friendships, where they noticed their social network had decreased. Friends that they had before the injury were no longer seen. One person described the lack of someone *in whom to confide*. Several participants felt that it was easier to stay inside than to go out. Fears prevented some from going out, such as being fearful of being hit by a car again, falling, or getting lost due to decreased memory. Others acknowledged not being able to do things like before and always needing someone to help them; therefore, they tended to stay indoors.

“I don't go out, I don't do anything. I'm only in the house.”

(P616, male, moderate TBI, 6 months post)

SELF-CONCEPT

Supplemental Table 2 depicts the representative quotes, themes, and subthemes for the self-concept meta-theme. No theme pattern differences in perspectives of self-concept were found based on years in the US (5 years vs. >5 years) and injury severity (mild vs. moderate-to-severe).

Maintained Self

When asked whether they believed that the TBI affected the way they view themselves, some participants (n=9; 38%) did not think so. They stated that they viewed themselves the same, as a *normal person* or *the same person as before*. Some acknowledged initial effects in the days following the injury, but did not believe there were long-lasting changes affecting their self-concept.

“Nothing has changed, as I see myself. Nothing has changed. Well, I feel that I see myself the same. I feel the same.” (P423, male, mild TBI, 8 months post)

Others acknowledged physical changes, such as *cut hair that will grow back*, *scars*, or *walking with four tires* (wheelchair), but still considered themselves the same.

“We are...normal, new people. We consider ourselves as a normal person. The only impediment is that we do not walk and we can't do things like others, but we consider ourselves as a normal person.” (P261, male, moderate TBI, 19 months post)

Loss of Self

The majority of participants reported viewing themselves as a different person compared to before the injury. They reported a loss of self, *soy diferente*. They viewed themselves as a different person, often due to changes in physical abilities or emotions. Others described their loss of self as a *total loss*, *loss of self-worth*, or loss of their ability to maintain their perceived social role (i.e., gender role conflict). Many perceived changes with work, school, friends, and social life.

Different Person—Perceptions of being a different person following injury were described in either percent change, or specific cognitive, emotional, or physical changes. Similar to how they described their QoL after injury, without prompting, some reported their changes to self in terms of percent differences, ranging from 4% to 80%. They viewed themselves as 100% or whole prior to injury and as incomplete following injury. For example, a participant felt 10-15% less every time he looked in the mirror to comb his hair, as it reminded him that he still needed to have another head surgery. Another participant felt 80% different because of differences in how he thought and what he could or could not do, and he described always wanting to cry because of his limitations.

“I feel different. Yes, like before [I was] 100%, now I feel like 70% to 80%.”
(P515, male, mild TBI, 6 months post)

Others felt different because of cognitive, emotional, or physical changes after injury. Some noticed changes in their thinking and the emotional toll the TBI had caused. They felt depressed when thinking about all of the consequences of the injury

“Emotionally. Yes, I am different because something will affect me emotionally fast. For example, when I am here I want to cry or something. Quickly it makes things worse for myself. I quickly feel very sensitive....very sensitive.” (P217, female, mild TBI, 6 months post)

Others described the physical changes, such as the *inability to walk straight, severe headaches, decreased mobility, or weight gain*. One participant described not feeling the same because of a metal plate placed in his head that bothers him, saying, “*These materials in my body are not of my body.*”

“It [the TBI] has affected....I can’t walk very fast. I’m also getting fat.” (P557, male, severe TBI, 6 months post)

Total Loss—Nearly a third of the participants described the change to their self-concept as a *total change*. They described that the TBI affected multiple areas of their life, such as employment, cognitive and emotional changes, physical changes, social network changes, and how they see themselves. Despite maintaining hope for the future and faith in God, they believed that they would never again be the same person. Because of the perceived losses, a 29-year-old male participant felt that he was *dead in life* because he could not do the things in which he placed value. Therefore, in the moments of experiencing great losses following TBI, Spanish-speaking immigrants often used their faith to guide their recovery and view of self.

“A great loss.”(P615, 84-year-old male, mild TBI, 12 months post)

“Wow! Completely, I was on the positive side, and now I’m on the negative side. So, my status changed...by my studies, my job, so much by my job, so much for friends, everything changed. Right now, I’m at home doing nothing, that is, it changed completely. (P130, female, severe TBI, 8 months post)

Loss of Self-worth—Because they viewed their lives and themselves differently, they described not having self-worth or feeling worthless. Some also mentioned that they felt that others no longer saw their worth and no longer needed them as before. For some, decreased abilities and/or inability to work, negatively affected how they viewed themselves, or perceived credibility from others. One participant described isolating himself from others because they say incorrect things around him and it only causes anger, stress, and emotional distress.

“Like right now...I don’t feel like I’m anything. I feel, who knows, like I’m worthless.” (P050, male, moderate TBI, 11 months post)

Gender Role Conflict—Only a few male participants described how they viewed themselves differently in terms of not being the man as before and being afraid of helping around the home. One mentioned how the TBI affected his life 100% and that he struggled with coping with the fact that he is no longer working and hoping that his wife is able to support him. Aware of their changes, they try to help their wives as much as they can with caring for their children, while they are no longer working and providing for the family.

“100%. In that, I’m not how I was before. I can’t be how I was before. I feel very sad. I feel down. I’m not the man I was before who pitched in with many things. Waiting for my wife to take care of me because it has 100% affected my life.” (P161, male, severe TBI, 11 months post)

Discussion

This qualitative study uniquely adds to the literature base by providing a unique glimpse of the lived experiences of non-US born, Spanish-speaking immigrants with TBI living in the U.S., who are an underserved and underrepresented population in rehabilitation. Considering that most participants received no rehabilitation services following injury, the most frequently mentioned facilitators of QoL were faith/religion and maintaining a positive outlook on life. Nearly all of the participants were actively practicing their religion and relied heavily on their faith and relationship with God to guide their positive outlook on life and recovery. In a national survey of Hispanics in the U.S., 61% reported that religion is very important in their lives, and religiosity is greatest among immigrant Hispanics compared to those who are 1st-3rd generation [38]. Hispanics often report an external health locus of control, where they rely solely on God to determine their health [39, 40].

Although religiosity has not previously been explored in depth among Hispanics with TBI, prior studies have found the importance of religion and spirituality among persons with TBI. Actively practicing a religion was associated with greater misconceptions about TBI among ethnic minorities, with Spanish-speaking persons with TBI reporting greater percentage of misconceptions than English-speaking Hispanics and Blacks [23]. Other TBI-related studies have found that religion and spiritual beliefs uniquely predict post-injury psychosocial outcomes [41, 42], and vulnerability is often perceived through the awareness of God's relationship to their mortality [43]. Additional work is needed to further explore the role of spirituality and religion in conceptualizing the injury, making sense of its consequences, reconstruction of self-identity, and supporting post-traumatic growth and resiliency in Spanish-speaking US immigrants with TBI.

Similar to the results from previous studies with only English-speaking populations [28, 44, 45, 46], we also found that the consequences of injury (cognitive, physical, emotional, social, employment) negatively affect the QoL and self-concept of Spanish-speaking immigrants with TBI following injury. Participants perceived that their injury disrupted lives, causing them to focus on barriers to recovery, such as changes in employment and financial situation, fears or uncertainty about the future, and decreased social and community participation. The changes noted after injury resulted in the majority of participants viewing themselves differently or as a different person following injury. In earlier studies of sense of self following acquired brain injury, relationships with others and coping strategies were an important part of regaining a sense of self after injury [47, 48].

Although many participants acknowledged changes in their relationships as result of injury, they did not perceive relationship changes as a reason for feeling different or loss of self. Instead, they focused on the physical, cognitive, and emotional changes that made them feel dissimilar from their pre-injury selves. A meta-synthesis on studies exploring the TBI recovery experience revealed that people with TBI may have strong feelings of loss — social disconnection, disconnection with pre-injury self, and mind/body disconnection — which results in negative emotional sequelae after injury [28]. This is consistent with the disconnection with pre-injury self (i.e., different person) and mind/body disconnection (i.e., TBI physical and cognitive sequelae) described by the Spanish-speaking immigrants.

This study significantly contributes to the literature by exploring the experiences of Spanish-speaking individuals with TBI in the US, where current research is minimal [20]. It is important to understand the different contexts and experiences reported by Spanish-speaking immigrants following injury. In some cases, the TBI occurred within months of them arriving in the United States, and most, if not all, received no rehabilitation services following injury. Even when undocumented immigrants during acute care receive a recommendation for inpatient rehabilitation based on a physical therapy evaluation, many patients are discharged home without services [49]. Spanish-speaking Hispanics have the greatest rates of severe disability and are also less likely to have medical insurance, which reduces their odds of receiving post-TBI rehabilitation services [50]. Recently, health care workers communicated their shared concerns about undocumented Hispanic immigrants interacting with health and social services, as it may lead to deportation because of the Immigration and Customs Enforcement (ICE) under the current U.S. administration [19].

Recent studies have continued to demonstrate the disparities in access to rehabilitation services for Hispanics with TBI [11, 51, 52]. Without medical insurance, the participants had limited or no access to needed health care services, such as when one participant described going for an extended time without a bone flap replacement. Policies can influence the access to care following TBI among immigrant populations. The undocumented population in Texas is steadily growing, and current policies make it challenging for them to access medical insurance coverage [53, 54]. As evidenced by the words of one of our participants, fear regarding deportation results in feelings of vulnerability after TBI, and may disincline these patients to seek out needed medical and rehabilitation services. Non-English-speaking Hispanics experience significant barriers to accessing medical services, receiving quality care, and achieving optimal health outcomes [55]. Undocumented immigrants with TBI experience similar healthcare disparities as racial/ethnic minorities with TBI in the US [56, 57].

The findings from the current study have implications for rehabilitation professionals treating Spanish-speaking immigrants with TBI. They should be aware of the special issues faced by this population that may impact recovery. For example, they may need assistance identifying and accessing follow-up medical services and other resources. They may need to be reassured that accessing medical care will not result in penalties due to their immigration status. Given that some participants perceive their Spanish language as a barrier to recovery, availability of Spanish-speaking health professionals and Spanish language education materials should be a priority. Faith and positive thinking in this population can be utilized to build resiliency skills when coping with TBI-related difficulties. Professionals should be aware that some immigrants might be leaving situations in their countries of origin that are worse than the consequences of the TBI, and that this context may influence their perception of the TBI and their response to interventions.

In addition, national and state-level brain injury organizations should consider advocating for improved healthcare access for undocumented persons with TBI from Latin America. Forming partnerships with organizations that are dedicated to serving persons from Latin America in the US such as, the UnidosUS and the League of United Latin American Citizens, may be beneficial. Other engagement strategies might include developing

Spanish-language educational materials, creating marketing campaigns regarding how to access services, collaborating with community-based organizations (e.g., religious/faith organizations, health centers, and community centers), advertising or special programming on Univision, creating YouTube informational videos, and sharing information on social media platforms. The aforementioned engagement strategies may help bridge the information gap and address the access to care needs of Spanish-speaking US immigrants with TBI.

Limitations

While attempts were made to recruit consecutive TBI admissions to a Neurosurgery intensive care unit, recruitment was conducted at 6 months following injury, and not all Spanish speakers with injury could be located at that time. This created a bias in the sample toward Spanish-speaking immigrants who remained in the United States and had a stable living environment at 6 months after injury. The sample consisted of persons with mostly complicated mild TBI, and the results may not be generalizable to those with moderate to severe TBI. The sample was heterogeneous in terms of their countries of origin and their time in the United States, which may influence their perceptions of the consequences of injury and course of recovery.

Conclusions

Spanish-speaking US Hispanic immigrants held a strong faith and positive outlook after TBI in spite of the significant barriers to recovery. Rehabilitation professionals should be aware of the unique positive and negative perceptions of this population and their limited access to care and resources so that they can tailor referrals and treatments appropriately and develop programs to support creatively their recovery.

One participant nicely summed up the unique experiences of Spanish-speaking immigrants who sustain a TBI in the United States:

“That’s life and God knows why. And here we are struggling in this country because the opportunities in this country aren’t available over there [in our country]. It’s never available there... Here we are struggling for life. And we will continue until we are fine. Let’s see how it goes, God willing. If God wants to take us, let it be.” (P507, male, mild TBI, 6 months post)

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Implications for Rehabilitation

- Spanish-speaking US Hispanic immigrants may experience significant barriers to care following traumatic brain injury (TBI), such as access to rehabilitation services and follow-up care.
- Rehabilitation professionals should consider the importance of faith and encourage positive thinking and social support when working with Spanish-speaking US Hispanic immigrants on how to cope with TBI-related challenges.
- Access to Spanish-speaking rehabilitation professionals, translators and Spanish language educational materials could help reduce language-related barriers to recovery among Spanish-speaking US immigrants with TBI.
- Rehabilitation facilities should develop partnerships with community-based organizations serving the uninsured or underinsured to address the access to rehabilitation and medical needs of Spanish-speaking US immigrants with TBI.

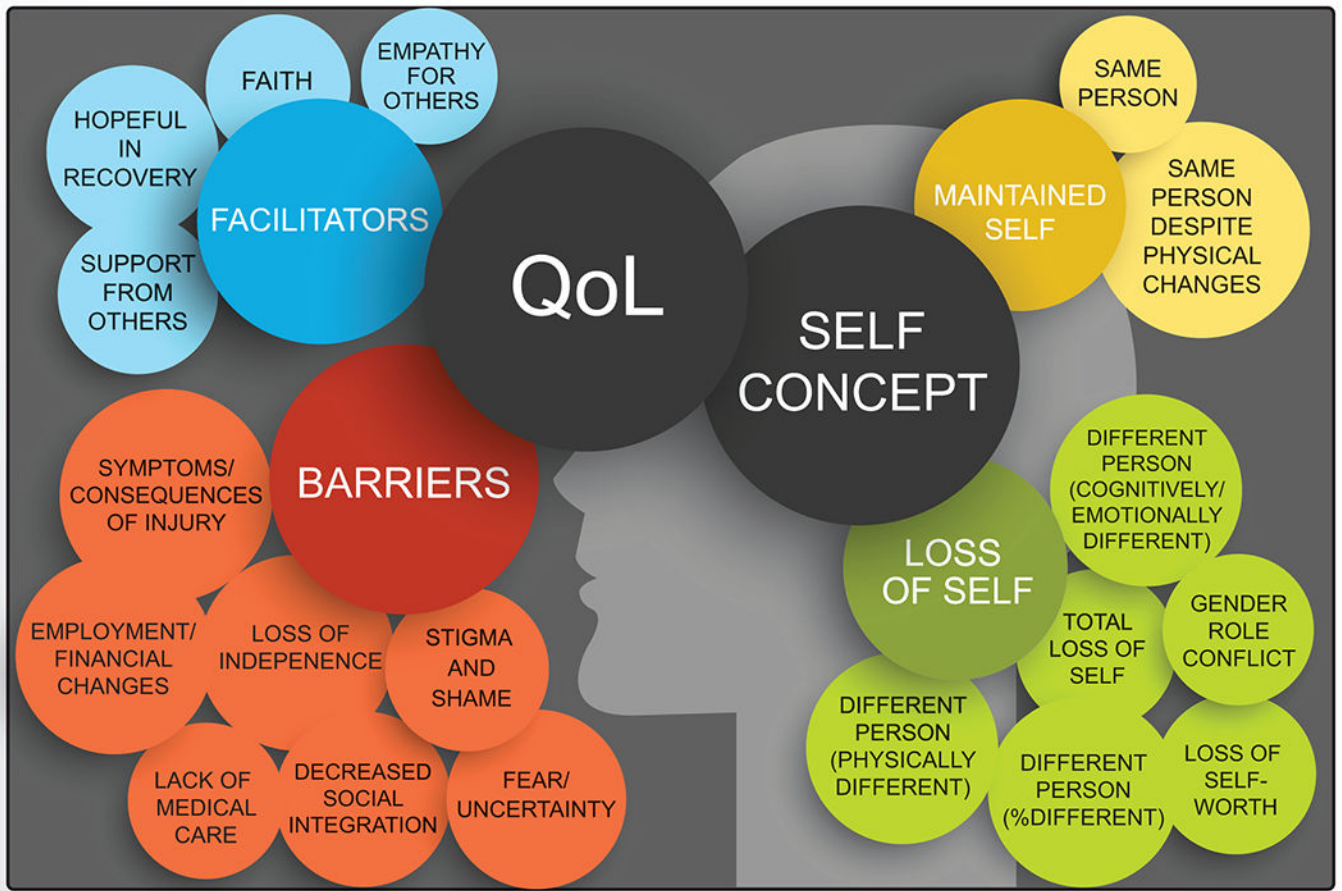


Figure 1. Thematic Network of Quality of Life (QoL) and Self-Concept following Traumatic Brain Injury.

Table 1.

Demographic characteristics (N=24)

Time post injury	
mean months (SD) [min-max]	9.29 (4.60) [6-21]
Time in the US	
mean years (SD) [min-max]	10.54 (9.66) [1-36]
Injury Severity	
Mild	13 (54.2)
Moderate	5 (20.8)
Severe	6 (25.0)
Age	
mean (SD) [min-max]	38.17 (16.92) [19-84]
Gender, n (%)	
Female	5 (20.8)
Male	19 (79.2)
Education	
mean years (SD) [min-max]	6.96 (3.96) [0-16]
Income	
\$20K	13 (65.0)
\$20,001K - \$40K	5 (25.0)
>\$40K	2 (10.0)
Marital Status, n (%)	
Married/Cohabiting	12 (50)
Never Married/Separated/Widowed/Divorced	12 (50)
Live with, n (%)	
Spouse/Significant Other	8 (33.3)
Parent	3 (12.5)
Other relative	8 (33.3)
Friend/Roommate	4 (16.7)
Alone	1 (4.2)
Country of Origin, n (%)	
El Salvador	5 (20.8)
Guatemala	3 (12.5)
Honduras	4 (16.7)
Mexico	12 (50.0)
Pre-Injury Productivity, n (%)	
Employed	21 (87.5)
Homemaker	1 (4.2)
Non productive	2 (8.3)
Post-Injury Productivity, n (%)	
Employed	9 (37.5)
Student	1 (4.2)

Homemaker	1 (4.2)
Nonproductive	13 (54.2)
Mechanism of Injury, n (%)	
MVA/MCA	8 (33.3)
Auto-pedestrian	3 (12.5)
Fall/ Jump	4 (16.7)
Assault	7 (29.2)
GSW	1 (4.2)
Hit by Object	1 (4.2)

Note. SD: standard deviation; MVA: motor vehicle accident; MCA: motorcycle accident; GSW: Gunshot wound.

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Table 2.

TBI-related Experiences by Themes, Categories, and Codes

Theme	Category	Code Examples
Facilitators of Quality of Life	Faith	Attend church more often God
	Hopefulness in recovery	Being optimistic Move forward with life Resiliency
	Empathy for others with disability	Understand pain of others
	Support from others	Support from family/friends Support from support group
Barriers to Quality of Life	Decreased Social Integration	Decreased social network Decreased participation in activities
	Employment/Financial Changes	Decreased working abilities Unable to work
	Fear or Uncertainty	Fear of sustaining a second injury Uncertainty about future
	Loss of Independence	Limited Need assistance
	Lack of Medical Care	Difficulty obtaining care Need surgery or procedure
	Stigma and Shame	Shame Treated differently
	Symptoms or Consequences of Injury	Cognitive Emotional Physical
Maintained Self	Same Person	Feel normal No effect from the TBI
Loss of Self	Different Person	% different (e.g., 4%, 20%, 90%) Cognitively/Emotionally different Physically different
	Gender Role Conflict	Assistance with maintaining family Not the same man
	Loss of Self-worth	I am nothing