

Traumatic Brain Injury in the Muslim Community: Addressing An Underserved Population Through Partnerships

First International Conference on Culture, Ethnicity, and TBI Rehabilitation

Rooshey Hasnain, Ed.D.
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University of Illinois at Chicago
Department of Disability & Human Development

Agenda

- ◆ Who are Muslims with traumatic brain injury (TBI)
- ◆ What are the major causes of TBI?
- ◆ What we know about brain injuries in Muslim communities
- ◆ How do quality and disparities intersect in relation to the Muslim culture?
- ◆ Need for more cross-cultural TBI research
- ◆ Next Steps

The Problem

- ◆ Little is known about how Muslim TBI survivors experience brain injury and/or brain injury rehabilitation.
- ◆ Muslims with brain injuries are a minority client population within the current U.S. rehabilitation service delivery system.
- ◆ Few U.S. studies focus on the numbers, status, and needs of Muslims with brain injuries and their families and/or caregivers.
- ◆ Due to the stigma, Muslims with TBI lack a collective voice and find themselves with limited options or opportunities in their communities.

As disability service providers and researchers, we need to pay more attention to the needs of this under-represented and underserved population group.

(Hasnain, Shaikh, and Shanawani, 2008)

Key Messages:

- ◆ Heighten awareness, need, and issues that affect Muslims with TBI
- ◆ Become familiar with the various cultural barriers and strengths Muslims from various backgrounds bring to the care of individuals with TBI
- ◆ Increase partnership strategies to improve access and service options for Muslim TBI survivors and their families





Major Causes of Brain Injury, Globally

Brain injury is known to be the leading cause of death and disability...

- Road traffic-23%
- Unintentional injuries-18.1%
- Suicide-16.9%
- Violence-10.8%
- Falls-7.5%
- War-3.5%

(WHO, 2002)



Leading Causes of Traumatic Brain Injuries in Muslim Countries

- ◆ TBI is 9th leading cause of disability worldwide
- ◆ Head injuries: 52.8%-70% are a major cause of death, injury, and disability (WHO, 2004)
- ◆ The rate of fatalities due to falls and accidents is 6 times higher in low versus high income countries

QuickTime™ and a decompressor are needed to see this picture.

(Nandiyaya & Reich, 2002)

Crowded Buses/Trains

Other Examples of TBI

QuickTime™ and a decompressor are needed to see this picture.


Benazir Bhutto died from a head injury in blast, ...

(from <http://www.guardian.co.uk/world/2008/feb/08/pakistan.marktran>)

Falls from Date Palms:


(Al-Adawi et al., 2007; Raja et al., 2001)

- ◆ In Oman, this cause of TBI is also a growing public health problem
- ◆ Better emergency care, transportation, and medical management have helped decrease mortality rates
- ◆ Just like the U.S. increased survival has resulted in the greater need for long-term rehabilitation



Mother of Fallen Muslim-American Soldier

QuickTime™ and a decompressor are needed to see this picture.



Kareem Rashad Sultan Khan

The Challenges

Size of the population: One billion (1/6 of world's population) is Muslim; 2.35 to 7.5 million reside in the U.S. (Pew Research Center, 2007; Islam, 2001); many of who may have a TBI

The consequence of increased number of Muslims in the U.S. creates a greater need for TBI research and service delivery

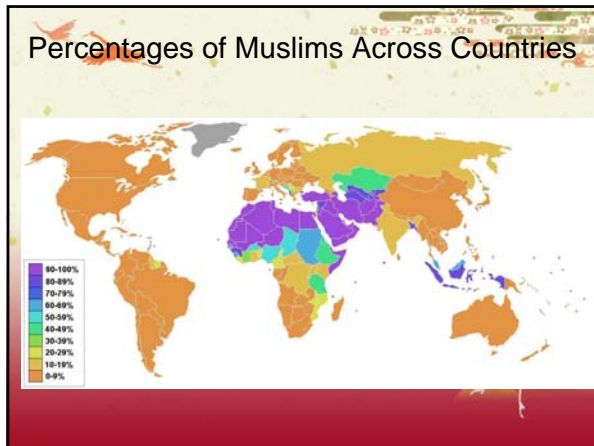
Muslims face:

- Higher levels of racism and discrimination
- May lack an understanding of TBI rehabilitation and its benefits
- May carry a sense of shame about a member's disability
- Limited access to culturally and linguistically appropriate TBI rehabilitation services

The Muslim World

Muslims:

- ◆ Come from 65-100 different countries
- ◆ Are diverse in language, dialects customs, traditions, political experiences, and health beliefs (Shamshad & Crown, 2005).
- ◆ Comprise the majority population in 30-40 countries with the world's largest community in Indonesia and parts of Asia and most of Africa.
- ◆ Comprise significant minorities in many other regions of the world, (China, North and South America, and Europe).



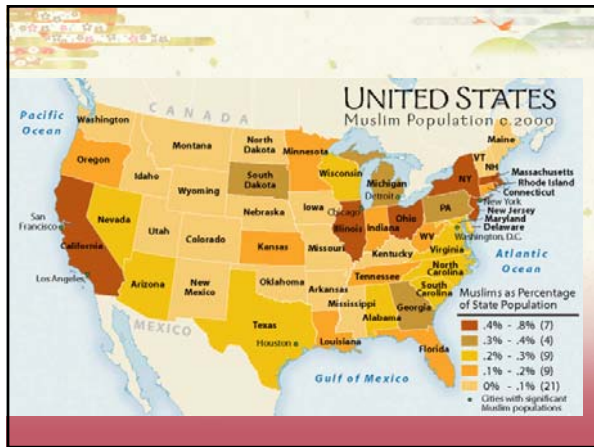
Race and Ethnicity

- No single racial group constitutes a majority among Muslims in the U.S. population:

Foreign-born Muslims are:

- 44% White
- 28% Asian, and
- 18% mixed or other.
- 10% are Black.
- 4% say they are Hispanic/Latino

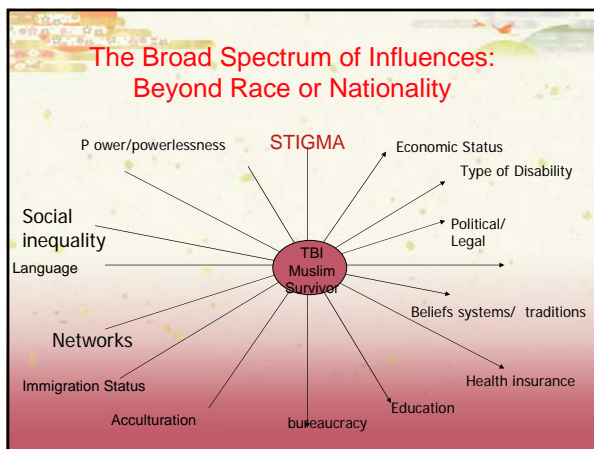
So, it is often difficult to know if a person is Muslim unless we ask questions about religion in our data collection efforts



So, What is Culture?

- 100s of definitions
- A system of shared beliefs attitudes, values, goals, and practices that characterizes an institution, organization or group.
- Provides a sense of security, integrity, belonging
- Constantly evolving
- Multi-faceted: varies across systems and levels

But overall, it is difficult to define due to variations in people's experiences and how factors play out both internally and externally In families, communities, and systems.



Culture Matters to TBI Care in Muslim Communities

Barriers to Seeking Help
-Mild TBI may go unrecognized unless behaviors are upsetting or disruptive

Social stigma often more pervasive than in other ethnic and racial groups.
-Family members may view TBI as God's will (e.g., reward, blessing, or a punishment)

Family Name/Saving Face
-Preserving social standing may cause both individuals and families to look internally for help rather than risk being viewed negatively by others

Issues of Diagnosis or Evaluation of TBI
-Misdiagnosis from over or under reporting by family members of actual symptoms or behaviors

Issues of Accessibility and Understanding of rehabilitation service care options and treatment

Myth vs. Reality

MYTH The *Qur'an* (Islam's holy book) says people with disability are inferior to able bodied people

REALITY The *Qur'an* does not refer to people with disability as inferior. In fact, the following references can be found:

- ◆ Disability makes no difference to the status of any human being. A person with a disability deserves the same attention and respect as any able bodied person.
- ◆ It is very bad to ignore a person with a disability (Qur'an: 80: 1-13)
- ◆ People with disability have granted special permission to obtain their needs (Qur'an: 16:62).
- ◆ It is a grave sin to ridicule anybody on basis of his/her disability.

How Do We Study TBI, Cross-Culturally?

- ◆ Muslims and/or social service systems may use other terms and labels
- ◆ TBI may be misidentified as mentally ill or learning disabled by Muslims
- ◆ Misconceptions are easily formed by TBI survivors and their families and communities depending on visibility or invisibility of their disability

(Swift & Wilson, 2001)

Muslim TBI Survivors & Their Families...



- ◆ A powerful sense duty and interdependence within families particularly during difficult times.
- ◆ The U.S. rehabilitation model emphasizes client autonomy but this conflicts with Muslim's emphasis on family

(Al-Adawi et al., 2007; Yamey et al., 2004; Kausar et al, 2009)

How Many Muslims View Disability or Injury within the Context of Rehabilitation

- ◆ In the Islamic world, life is seen as an examination or a test of faith. Injury or illness is seen as part of this test.
- ◆ Ill health is often viewed as being predestined by God
- ◆ Muslims are encouraged to use whatever means that are available to rehabilitate themselves
- ◆ If recovery is not likely, they are encouraged to practice, patience, resilience, and gratitude towards God

(Yamey & Greenwood, 2004)

Definitions-What does disparity mean in Rehab?

- ◆ **Rehabilitation Disparities:** Differences in the presence of disabilities, rehabilitation outcomes, and access to rehabilitation among specific population groups in the United States
- ◆ **Rehabilitation Care Disparities:** Differences in rehabilitation care or treatment provided to members of different ethnic and racial groups that is not justified

Although disparities in rehabilitation and rehabilitation care can be tied to one another, it may be important to distinguish between them to increase our understanding of the complexity of the problem.

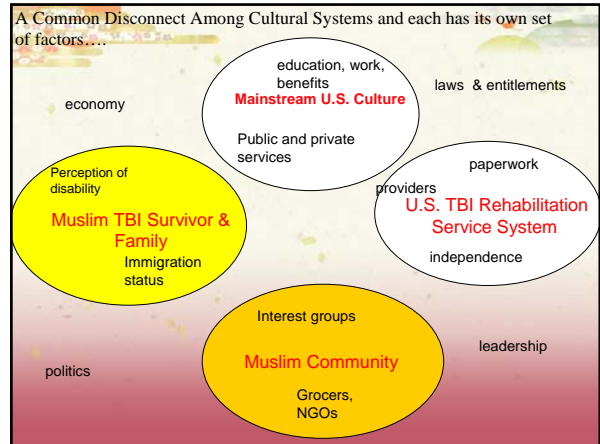
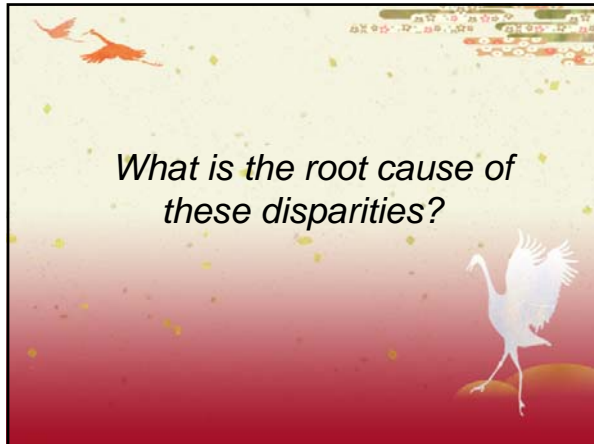
(Adapted from Hasnain, 2008)

Racial and Ethnic Disparities Associated with African American and Latinos in Rehabilitation Care

- ◆ Less access to TBI rehabilitation care
- ◆ Longer wait time to see a provider
- ◆ Less likely to be sent back to referring physician after discharge
- ◆ Fewer therapy services (OT, PT, speech, counseling) and hours during in-patient rehabilitation
- ◆ Higher levels of disability
- ◆ Lower levels of social integration and community productivity 1 year after injury
- ◆ Less likely to return to work or productive activities...

But is this also true of Muslims with TBI?

(Arango-Lasprilla & Niemeier, 2007)



Multi-Factorial Reasons Behind Service Gaps:

Family/Individual Differences
 -Denial of TBI or misperception of the condition
 -Lack of understanding about benefits of rehabilitation

Provider Differences
 -Provider-consumer communication breakdowns (language, cultural beliefs, etc)
 -Stereotypical thinking and bias

Muslim Community Differences
 -Mistrust and fear of rehabilitation service system

TBI Rehabilitation Differences
 -jargon, paperwork, conflict with mainstream, middle-class values/principles

All of these factors can lead to poorer outcomes and quality of life for TBI Muslim survivors

These Influences Hinder and/or Facilitate the TBI Survivor's Ability to Achieve....

- ◆ MEANINGFUL OUTCOMES
- ◆ OPPORTUNITIES
- ◆ ACCESS
- ◆ WELL-BEING
- ◆ SOCIAL INTEGRATION
- ◆ QUALITY OF LIFE

BIGGEST NEEDS


- ◆ Need more qualified Muslim TBI rehabilitation providers and researchers
- ◆ Need for better access to long-term supports and services through non-traditional venues and media
- ◆ Need for better connectivity across services and agencies
- ◆ Need better access to appropriate TBI rehabilitation and therapies In Muslim languages

The Multiple Language Barriers that Hospitals Often Encounter:

Spanish	93%
Chinese	47%
Vietnamese	39%
Japanese	37%
Korean	37%
Russian	37%
German	36%
French	31%
Arabic	26%
Italian	26%
Laotian	23%
Hindi	22%
Polish	22%
Tagalog	21%
Thai	20%

The situation may not be any better in TBI Rehabilitation Centers... especially in regard to Muslim languages

Source: (HRET, 2006)



So how can we bridge the many service gaps that exist between Muslim TBI Survivors and the U.S. TBI rehabilitation system?


The Need for Cross-Cultural Partnerships



Steps Could We Take To Improve the Situation

- Increase representation of Muslim TBI survivors in U.S. research and service delivery efforts.
- Improve data collection to better assess status, needs, and strengths of Muslims with TBI and their families.
- Improve advocacy and leadership within the Muslim community and their interactions with rehabilitation and disability fields
- Improve accessibility and inclusive opportunities to engage Muslim TBI survivors in their communities

Successful Outcome of Rehabilitation



Next Steps

To design appropriate quality TBI interventions and materials, we need to:

- ◆ Improve outreach to U.S. based immigrant and refugee Muslim groups.
- ◆ Build culturally sensitive connections and partnerships and increase TBI research within the Muslim population.
- ◆ Develop culturally responsive assessment tools to improve the brain injury recovery process of Muslim TBI survivors
- ◆ To better address the unique adjustment needs of TBI survivors in the Muslim community, tap into experts, community members, and consumers and family members who have been affected.
- ◆ Conduct case studies to determine the influence of Muslim beliefs on TBI outcomes and rehabilitation service use.
- ◆ Pursue cross-cultural collaboration with Muslim countries to develop culturally relevant community-based models of TBI rehabilitation.



Disability & Exchange in the Muslim World

