

Qualitative analysis of
perceived environmental
barriers of people with
Traumatic Brain Injury (TBI)

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Collaborators

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Purpose

To examine qualitative responses regarding perceived environmental barriers and attempted solutions reported by participants who took part in an interview focusing on the long-term impact of TBI.

Assessment

- 243 individuals who received inpatient rehabilitation at the same comprehensive rehabilitation hospital after sustaining a TBI consented to be interviewed over the phone.
- The interview consisted a variety outcome assessments intended to better understand the process of aging with TBI
- The interview included the CHIEF and CHIEF-Follow-up Questionnaire

CHIEF

- Asks about 25 separate “elements” of the environment in a structured telephone interview.
- Each item is scored on frequency (How often is ___ a problem for you?) and severity (Is this a big or little problem for you?). The two are combined for a total product score for each element.
- 5 subscales have been identified through previous analysis (physical, policies, service, work/school, attitude).

CHIEF

Follow-up Questionnaire

CHIEF-FQ

- Gathers
 - Specific examples of environmental barriers.
 - Strategies of coping.
 - Effectiveness of the strategies.

CHIEF-FQ

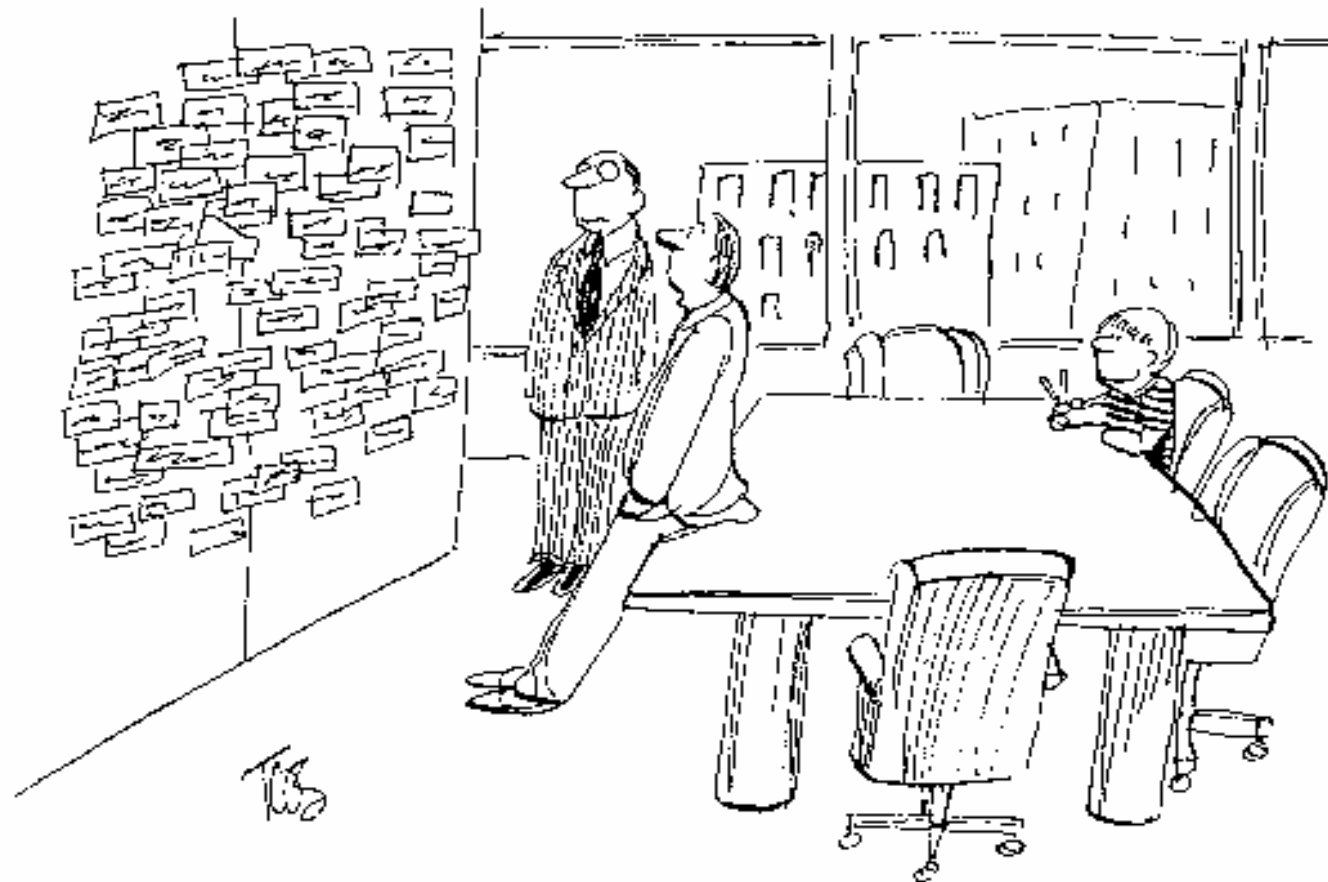
- 25 CHIEF questions
 - Identify the question with the highest product score (frequency of barrier X severity) in each of the 5 subscales.
 - Ask *“What specific situation did you have in mind when you said that ____ was a big barrier?”*
 - Each response = “critical incident”.
 - Ask *“What do you typically do in that situation?”*
 - Ask *“Does that usually solve the problem?”*

Demographics

- 148 of the 243 people interviewed reported experiencing a barrier at least once
- 45 Females, 103 Males
- The mean age was 43 year old
- The mean years post injury was 14 years (ages ranging from 18 years old to 73 years old)

Analysis

- Recorded interviews were transcribed
- Two independent researchers reviewed and coded transcripts for content
- More than 200 individual codes were identified
- Codes were collapsed into 10 categorical themes.



"We've broken your list into eighty-four subgroups. Our work here is done."

Themes

1. Emotional/Behavioral/Cognitive/Physical Changes following TBI
2. Discrimination and Stigmatization
3. Access and Transportation Barriers
4. Financial Problems
5. Employment Problems and Needs

Themes Continued

6. Rural Care Disparity
7. Climate Concerns
8. Relationships
9. Dealing Constructively with Changes Following TBI
10. Problems Dealing with Changes following TBI

Theme #1

“My Life is different in so many, many ways”

Emotional/Behavioral/Cognitive/Physical
Changes following TBI

Theme #1

Emotional/Behavioral/Cognitive/Physical Changes following TBI

“I used to work at the library, and I used to have to get books high up on the shelves, and they need ladders and stuff, and they require ladders, you know, and my job was to put the books back away. And, so I wasn't able to. I mean I would go and do it , but the thing is ...it's dangerous. I don't have any balance, I mean... [What] I was thinking about is the fact that they (potential employer) make no compensation for the fact that you don't have a sense [of balance] about you. You can do everything, but the fact that your balance is weak, there wasn't no...they would not hire you.”

Theme #2

“People do not understand by brain injury, and discriminate against me, and treat me unfairly”

Discrimination and Stigmatization

Sub-category

Invisible Injury

Theme #2

Discrimination and Stigmatization

“Like I said, I stay at home; don’t go out. I don’t want to get involved with nothing. I don’t do nothing because I’m scared ...Like people look at me, like I told you. I look normal , but I I I can’t think straight...so why even try? I’m not even going to try. I just can’t do it. I just, it’s too much of a struggle for me and I’m too , I’m too afraid of what other people are going to think about me. I don’t want anybody to laugh at me. And I think that they will. If they just see me...you know...the way...you know... the way that I act and that I don’t respond...And I’m just, I’m safe here in my home.

Theme #2

Invisible injury

“Because of my injury not being a physical thing that they can see. They don’t understand when I struggle with stuff.”

Theme #3

“It is very hard to get around my community for work, school, groceries, banking, doctors, or anything else that is important.”

Access and Transportation Barriers

Theme # 3

Access and Transportation Barriers

“I was thinking of driving myself to the doctor, which is like 12 miles away, or 15. And due to the fact that they (mountains) have so many winter visitors, and our population has expanded to like five million people... There’s a lot of, there’s a lot of activity and road work, road work, road work. So, driving, um any length of time or distance makes me anxious. [So], I talk to myself, turn the radio on, or just pull over.”

Theme #4

“I cannot afford my life since my TBI”

Financial Problems

Theme #4

Financial Problems

“They told my mother, that since I need [a] full-time caregiver, that she should quit her job, and come home and be with me all the time. And [they would] pay her as a caregiver (which the mother did)...And the program was going to get cut, and so then, here we are two years later, and they’re cutting it, and it’s hurting our budget. Well, it’s hurting the household...So, we’re gonna send me up to the governor to live for a week!”

Theme #5

“Work is important, but it is so hard to succeed at it.”

Employment Problems and Needs

Theme #5

Employment Problems and Needs

“Well, you know, because of my brain injury... Nobody wants to hire me, and I have a lot of physical problems... But employers out there don't want to, um, give you the opportunity to learn what they're doing, or get more hands-on training anywhere. I can't get trained for anything... And now all that money I spent on college is basically down the drain. Well, you know, there's a certain not a lot I can do.”

Theme #6

“It seems like the only cure is to move away from here.”

Rural Care Disparity

Theme #6

Rural Care Disparity

“Well, like I don’t have a driver’s license, and so I live in the mountains. We don’t have RTD (public transportation), no taxi service. I rely on friends for a ride, and that’s just [a] real hard situation. You know...people can’t wait on me.”

Theme #7

“The temperature makes me not feel good”

Climate Concerns

Theme #7

Climate Concerns

“I don’t know. I just get hot and I feel like I get overheated. And sometimes I feel like I could pass out or something.”

Theme #8

“My relationships are either gone or troubled,
which leaves me lonely”

Relationships

Theme # 8

Relationships

“Well, my children ... think that what happened to me happened to me. And that I have to live with it and I agree. I do have to live with it. But, they go about, you know, I hate to make it sound selfish, but they go about their deeds and, and, and have fun, and things, and they don't think about Mama. They never ask, “Would you care to go? Would you like to go with us?” You know, and I'm not saying like, you know something big, just like a show or something...No...they don't want to ask me.”

Theme #9

“I try to live with my life changes”

Dealing Constructively with Changes Following
TBI

Theme # 9

Dealing Constructively with Changes Following TBI

“Well as far as education, who do you educate, me or them?... [I] explain my situation and tell them what I need ... Sometimes it works; sometimes it doesn't.”

Theme #10

“Sometimes I do not deal well with the changes.”

Problems Dealing with Changes following TBI

Theme #10

Problems Dealing with Changes following TBI

“Well, I haven’t lived my life the way my family would like me to... And, and I do have problems in that, in that area because, because I, I, I, make bad decisions...I’ve been forced to sell [my home]. My, uh, my identity got stolen by them [my friends]... They got me involved with... Well I got myself involved with some drugs and stuff, and, um you know and I really, really, fell apart. And, uh, and now I’ve struggled with staying in with the right kind of people.”

Conclusions

- Despite great strides in disability over the last decades, many unresolved problems and challenges still exist for people with TBI living with cognitive and/or physical disabilities.
- Wide range of responses and approaches to coping or responding to challenges.
- People don't understand.
- Unmet need for education and information about TBI