

Towards Wellness in Acquired Brain Injury: The Unmasking Brain Injury Project

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Background

- Acquired brain injury (ABI) often results in a combination of physical, cognitive, communication, and emotional changes (Strong et al., 2007; Ponsford et al., 2013).
- People with ABI may need to modify, adapt, or change living environments, use assistive devices, or redefine social roles in relationships and productivity (Winkler et al., 2010; Doig et al., 2001; Ponsford et al., 2013; Douglas, 2019).
- Rehabilitation is best provided through considering a person holistically, as well as relative to their own individual goals (Jetter, 2006).
- Storytelling can support holistic rehabilitation and goal-setting for people with ABI (D’Cruz et al., 2017; Candlish et al., 2023). This approach can also serve as a tool for processing and communicating difficult experiences (Charon, 2006).
- In addition, targeting wellness can improve quality of life and feelings of purpose even as underlying disabilities may remain (Bezner & Hunter, 2001).
- The Six Dimensions of Wellness (Hettler, 1976, 1978) consists of interconnected domains (intellectual, occupational, spiritual, social, emotional, and physical) that contribute to a healthy lifestyle.
- These dimensions can offer perspective on how to consider a person holistically and emphasize the importance of person-focused and strengths-based approaches to support recovery and community reintegration (Wilson et al., 2009; Ownsworth, 2014; Togher et al., 2023).

Objectives

- Explore how individuals with acquired brain injury (ABI) use the Unmasking Brain Injury project to express their experiences, reflect on their condition, and educate their communities.
- Analyze how the six Dimensions of Wellness (DoW) and an additional dimension of recreation manifest in personal narratives, distinguishing factors that promote or hinder post-ABI wellness.
- Discuss the potential for using mask-making within rehabilitation and clinical settings to facilitate motivational interviewing, assessment, and treatment planning for individuals with ABI.

Participants

Participant Demographics	Masks created by ABI survivors n (%) (N=1019)
ABI Type	
TBI	681 (66.8%)
Stroke	190 (18.7%)
Other (brain infection)	148 (14.5%)
TBI Injury Mechanism	
Car accident	389 (57.1%)
Fall	88 (12.9%)
Physical abuse	55 (8.1%)
Not reported	55 (8.1%)
Struck by/against something	52 (7.6%)
Recreational/sports injury	30 (4.4%)
Multiple mechanisms	9 (1.3%)
Other	3 (0.4%)
Geographic Location	
Northeast	65 (6.4%)
Midwest	280 (27.5%)
South	351 (34.4%)
West	323 (31.7%)

Procedure

- Masks and their accompanying narratives from the Unmasking Brain Injury website (available as of 1/1/24) were manually screened and organized.
 - Only masks and narratives by people with ABI were included, family members or caregivers were excluded.
 - Mechanism of injury was coded, and developmental or degenerative brain injuries were excluded.

Data Analysis

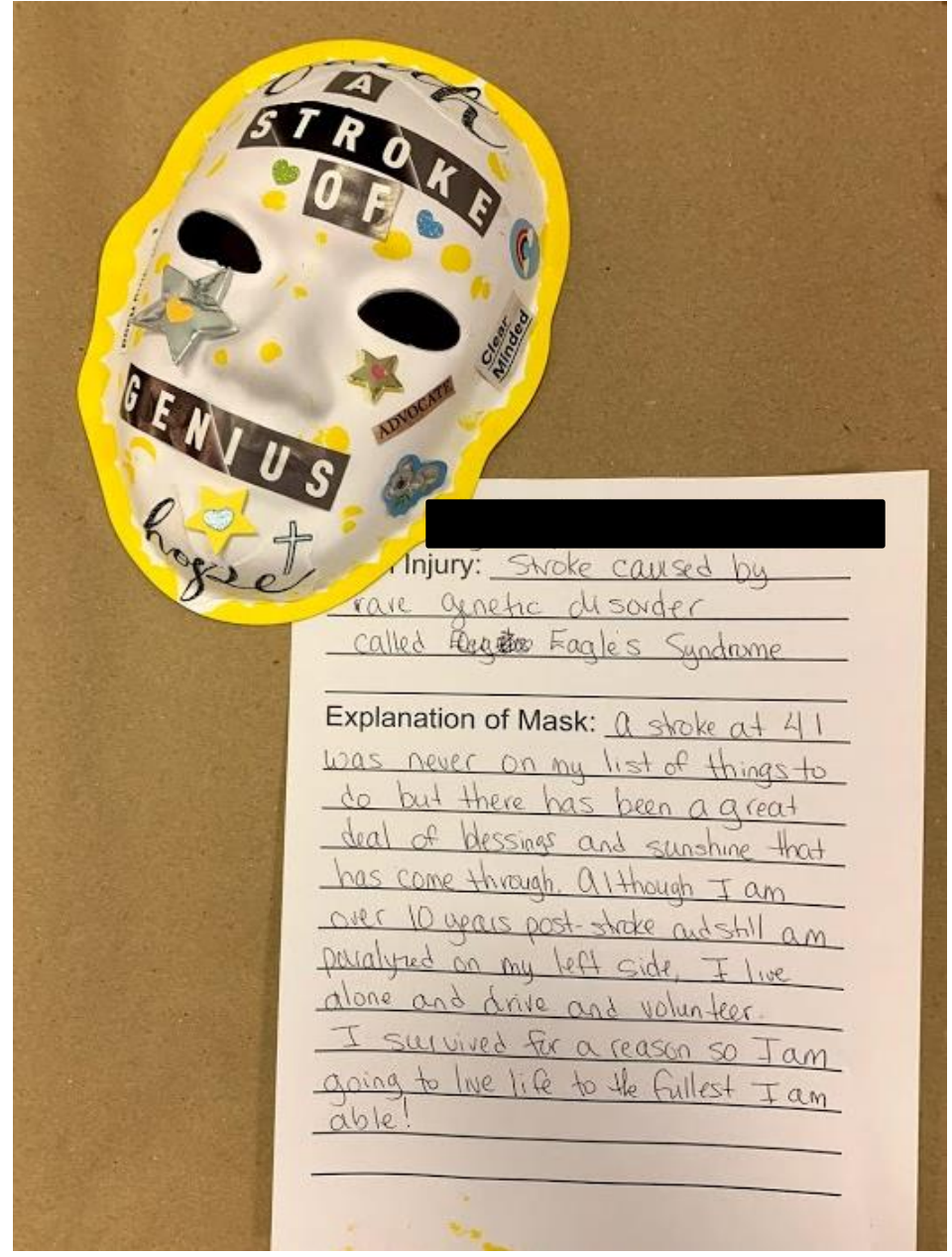
- The first and second author coded the first 150 narratives to develop the coding structure. Remaining narratives were coded by two trained undergraduate research assistants.
- Interrater reliability was completed for 10% of Phase 1 and Phase 2, resulting in 97% agreement.

Methods

- Phase 1: Document-level Content Analysis**
 - Used grounded theory processes of initial coding and focused coding to develop codes, themes, and subthemes of narratives overall.
- Phase 2: Communication Unit (C-Unit) Content Analysis**
 - Deductively coded statements within narratives based on Hettler’s (1976) Dimensions of Wellness.
- Phase 3: Sentiment Analysis**
 - Employed MAXQDA’s natural language processing to determine each c-unit and full narrative aggregate sentiment.

Quality

- Member was checked by people with ABI who created masks, and professionals from the Unmasking Brain Injury Project to ensure analysis aligned with experiences by people with ABI.



Results



Phase 1: Document-level Content Analysis

Outward Sharing

Subthemes	Codes
Change	Loss/emotional pain/rejection
Faith	Faith/spirit/hope/luck
Recovery	Rehabilitation/journey

“I have no friends, and I feel alone. I have learned to accept my new life—but I regret I don’t have the life I thought I would have.”

“[my mask is] cat like because of the 9 lives. The odds of me surviving the accident was very slim.”

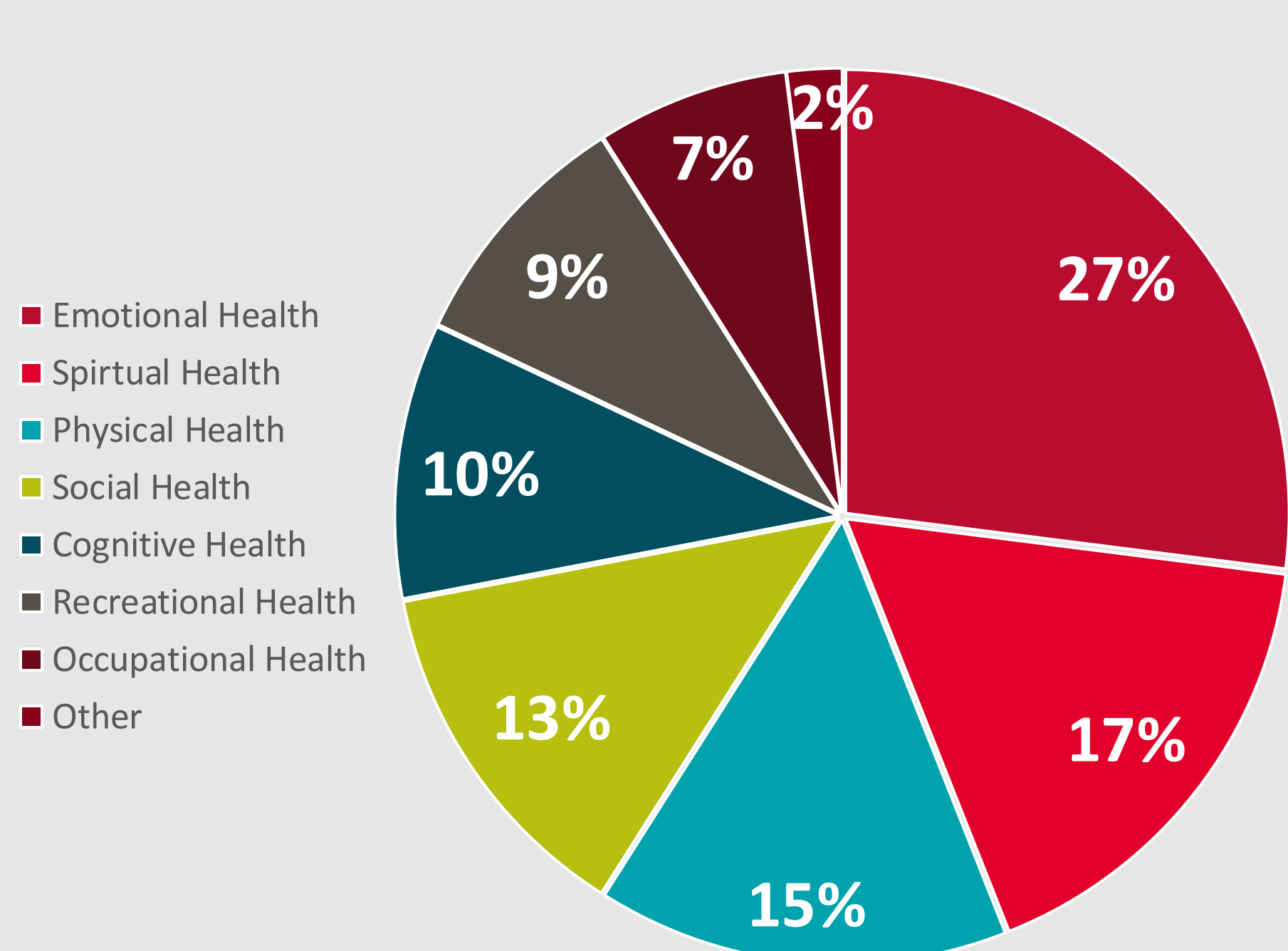
Inward Reflection

Subthemes	Codes
Acceptance	Personal attributes (e.g., determination, grit, strength, etc.)
Before/After	Reflecting/comparing life prior vs. current
Support	Support form family/friends/peers

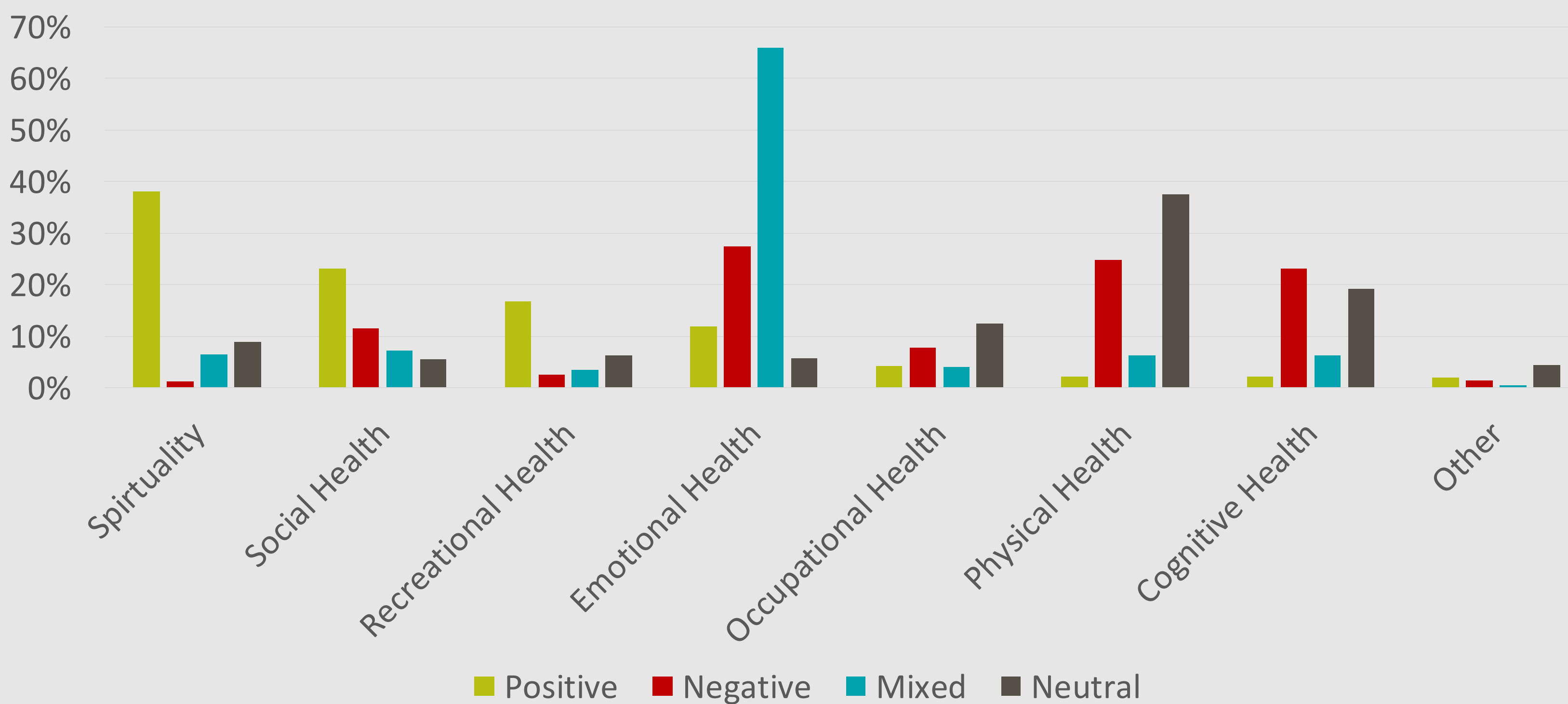
“Since my stroke, I feel slowed down, deliberate, not a slave to the clock, lead a more simple life, and have better management of time.”

“Although having to learn life’s new ‘norm’ has been a long road of challenges, I would still choose this norm over my pre-accident norm. My TBI doesn’t define me, but instead I define the presence and role my TBI has within my life.”

Phase 2: Dimensions of Wellness (C-Unit)



Phase 3: Sentiment Analysis



Discussion

- The Unmasking Brain Injury project supports people with ABI in creating masks about their experience with their injury. This provided an opportunity for people to share and reflect on their stories.
- Most narratives focused on outward sharing, with the purpose of helping others understand, advocating for their needs, or expanding representation of ABI.
- For narratives focused on inward reflection, storytelling may be a way to process the injury (change, personal growth, loss), which thereby may foster greater adjustment.
- By virtue of dedicating time to process and evaluate the injury, storytelling may serve as a modality for people with ABI to share and reflect on their experiences and changes.
- In almost all narratives, emotional, spiritual, physical, social, and cognitive health were represented. The inclusion of recreational wellness as an emergent theme suggests the importance of leisure activities in recovery.
- Sentiment analysis revealed that most positive statements were in the domains of spiritual, social, and recreational health, all of which are considered integral components to holistic recovery (Martin et al., 2017). While negative physical, cognitive, and emotional sentiments may serve as barriers for wellness.
- Mixed sentiments were most often related to emotional health, reflective of the process of evaluating pre- and post-self, the effort of recovery, and changes that occurred due to the injury.
- These results support integrating expressive arts-based interventions in clinical and rehabilitation settings to enhance holistic wellness.

Limitations

- Demographic data including age, gender, or socioeconomic factors were not available.
- Injuries could not be validated, nor time since injury, which may be important as those in the acute recovery phase may have different reflections than those in more chronic stages.
- Participants who elect to create and share a mask and narrative may not represent the broader ABI population. People with ABI have a variety of consequences post injury and therefore those who may need assistance in processing their injuries may not be captured through this analysis.
- Future research should explore longitudinal impacts of expressive storytelling in clinical rehabilitation.

Acknowledgements

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