



Unmasking Brain Injury: Using Art to Navigate Emotional Experiences in Acquired Brain Injury



WASHINGTON STATE UNIVERSITY
Elson S. Floyd
College of Medicine



Mary Frances Early
College of Education
UNIVERSITY OF GEORGIA

Erica Rawls¹ LCSW MEd, S. Kaytlyn Gregory² BS, Olivia Vruwink³ MS CCC-SLP, Beth Callahan¹ BA, Katy H. O'Brien^{4,5} PhD CCC-SLP, & Amy Kemp⁶ PhD CCC-SLP
¹Hinds' Feet Farm, Asheville & Huntersville, North Carolina; ²Department of Hearing and Speech Sciences, Vanderbilt University; ³Department of Speech-Language-Hearing Sciences, University of Minnesota - Twin Cities; ⁴Department of Communication Sciences and Special Education, University of Georgia; ⁵Courage Kenny Rehabilitation Institute, Allina Health; ⁶Department of Speech and Hearing Sciences, Washington State University

Background

- Acquired brain injury (ABI) is a major genesis of health problems and disabilities in adults worldwide, and includes both traumatic and non-traumatic brain injuries (Bracho Ponce et al., 2022; Goldman et al., 2022; Lannoo et al., 2004).
- The mission of the Unmasking Brain Injury Project (unmaskingbraininjury.org) is to spread awareness of brain injury and advocate for the needs of people with ABIs through the creation of masks.
- Prior literature has shown that emotional behavior can change as a result of these injuries (Henry et al., 2006; Kim et al., 2019; Ownsworth et al., 2008).
- These changes can disrupt the connection to their former self, societal roles, priorities, and abilities prior to injury (Beadle et al., 2016; Douglas, 2020; Glennon et al., 2022; Knight et al., 2020; Levack et al., 2010; Ponsford, 2013).
- By exploring new ways to share one's inner world with others, an individual can regain a sense of agency and connection with their new life (J. P. Jones et al., 2019; Umberson & Montez, 2010).
- Art offers individuals an avenue to relay more abstract concepts and emotions that are difficult to convey with words or lay beyond a person's linguistic abilities after injury (Puig et al., 2006).
- Mask-making has been involved in processing major life changes (Quinlan, 2016; Walker et al., 2017).
- Prior literature has observed a deficiency in psychosocial support options for families affected by ABI (Norman et al., 2020), as well as a gap in emotional care during transitions between inpatient and community services (Turner et al., 2011).

Objective

- The objective of this study is to categorize common emotional themes of people living with ABI that are expressed through mask-making.
- Two key questions informing our study:
 - (a) How does face-like art reveal the emotional experience of ABI?
 - (b) In what ways do artistic representations capture narrative themes of brain injury experiences?

Participants

Participant Demographics	Masks created by ABI survivors N (%) (n= 1,049)
ABI Type	
TBI	730 (69.5%)
Stroke	161 (15.3%)
Other (i.e., brain infection)	158 (15.1%)
TBI Injury Mechanism	
Car accident	375 (54.5%)
Other/Not Reported	82 (11.5%)
Fall	72 (10%)
Physical Abuse	52 (7.3%)
Struck by/against something	53 (7.4%)
Recreational/sports injury	29 (4%)
Multiple mechanisms	51 (7.1%)
Geographical Location	
United States	789 (75.2%)
Canada	256 (24.4%)
United Kingdom	4 (0.3%)

Methods

Procedure

- Masks available on the Unmasking Brain Injury website as of 3/1/2023 were manually screened and entered into an online database.
 - To be included in this analysis, data needed both an uploaded mask and accompanying description of the meaning of the mask elements, and be identified as an ABI injury (e.g., traumatic brain injury, stroke, or hemorrhage).
 - Exclusion criteria included any mask that did not specifically describe elements of the mask design, was created by family/caregivers or medical professionals, or identified as a developmental or neurodegenerative disorder.
- The final data set was uploaded to a software supporting qualitative analysis, MAXQDA 2022 (VERBI Software, 2021), to match the mask and accompanying description for data analysis. MAXQDA allowed the researchers to code and link meaningful units (e.g., color, symbol) and written description.

Data Analysis

- A qualitative data interpretation was completed in a hybrid inductive/deductive thematic analysis (Fereday & Muir-Cochrane, 2006; Proudfoot et al., 2023; Roberts et al., 2019) with two steps: an inductive (data-driven) approach and a deductive (theory-driven) approach.
 - Phase 1 of the analysis (first 300 masks) followed the phases of the thematic analysis as described by Braun and Clarke (2006):
 - 1) Familiarizing oneself with the data; (2) generating initial codes; (3) searching for themes; (4) reviewing themes; (5) defining and naming themes; (6) producing the report.
 - The full sample (N = 1,049) was then coded in Phase 2 according to the codebook developed by the analysis completed in Phase 1.

Rigor

- To protect the analysis against undue influence, an audit trail, peer debriefing, and member checking were completed throughout both phases.

Results

Theme 1: The Multiplicity of Experiences After ABI: the Positive, Negative, and Mixed

Almost half of the artists (45.5%) described feelings of juxtaposition related to their sense of self and emotional elements. Masks under this theme were visually divided into sections or contained contrasting colors, images, and symbols.

- Pre-and Post-injury Self Comparisons:** Artists visually compared a "before" and an "after" ABI. Change in skills, occupations, personality traits, and social support were depicted on these masks.
- Use of Colors, Symbols, and Images to Represent a Myriad of Emotions:** Artists either listed a variety of emotions experienced (and what mask elements represented them) or described ranges of emotions associated with specific events in their experiences with colors, symbols, or images



Mask #635



Mask #591

Theme 2: Emotional Pain and Living With Loss Can Be Revealed Through Art

Emotional pain and living with loss was the largest theme across the artists' masks (71.9%), of which 26% were solely dedicated to pain and grief. Loss was expressed as lost hobbies or passions, while emotional pain surfaced as feeling stuck or trapped in the current self. Masks often contained dark color palettes, tears, frowns, or crossed-out or removed features.

- Invisibility: Unmasking Hidden Experiences of ABI:** Artists symbolized hidden or unseen parts of their experience by contrasting sides of the masks, as seen in Theme 1, removing or blocking the eyes or mouth, or mixing smile and frowns on the mask



Mask #649



Mask #212

Theme 3: Positivity, Purpose, and Faith Are Important Aspects of the Experience With ABI

A portion of artists (21.6%) described how positivity, purpose, faith, or optimism were represented in their experience with ABI. Artists used encouraging or positive words/phases on their masks, bright colors, positively-attributed symbols, symbols of strength or power, as well as spiritual symbols.

- Meaningful Participation: Opportunities for People With ABI to (Re)connect With Their Chosen Communities:** Artists described ways in which support was influential to their own experience, including personal attributes, social support from a community, or spirituality. Masks depicted themselves as leaders and meaningful participants in their communities and activities



Mask #568



Mask #582

Positivity,
Purpose, Faith
(n=227)

Multiplicity
(n=467)

Emotional
Pain/Loss
(n=754)

"This mask represents the complete opposites between pre-injury and post-injury and yet also represents that after accepting their new normal, a new version of the survivor is revealed and a new journey begins." – Artist #635

"Like the flowers on my forehead, I'll boom once again. It could take years, but I chose to be hopeful about my future." – Artist #582

"My mask portrays the dark grey, black and blue matter that occurred with accident. The brain injury created dark shades of my life being lost... My mouth is closed because I often feel underheard especially by medical and disability systems." – Artist #649

Discussion

- Our findings support previous findings of positive (e.g., new skills, re-evaluation of life priorities) and negative attributes (e.g., loss of autonomy, inabilities) that people with ABI identify (Lennon et al., 2014; Ownsworth, 2014).
- The experience of traumatic events can create obstacles in reconstructing a sense of personal identity, which includes the process of recognizing a meaningful life story (Shadden et al., 2008).
- Art may offer a method to facilitate conversations related to a person with ABI's experience, as well as facilitate goal setting for identity reconstruction (Ylvisaker et al., 2008).
- Furthermore, art may also be particularly helpful as other narrative approaches emphasize the need for co-construction (Candlish et al., 2023; Strong et al., 2018) and mask-making does not solely rely on language for expression.
- Art-based methods have been used with people with ABI as a method to improve communication, word-finding, and social reintegration (Douglas et al., 2020; Jones et al., 2016); especially for those that have consequential feelings of loss and grief.
- Art-based methods may also be an opportunity to explore how a person is situated within their own recovery from ABI, particularly in positive aspects, gains, or benefits from rehabilitation, support, or self-learning that one may have experienced.
- The Unmasking Brain Injury Project may be a demonstration of how art-based methods can be used as tools for expressing internal emotional experiences and sharing with external parties.
- Person-centered and trauma-informed care requires in-depth and open discussions about individual values and preferences (Bright et al., 2012; Cardol et al., 2002; Ward, 2012). Specific rehabilitation should focus on an individual's emotional experience, as well as address feelings of loss and grief.

Limitations

- Demographic data including age, gender, or socioeconomic factors was not available. Therefore more in depth characteristics of the artists was not possible.
- Additionally, injuries and time post injury was unable to be verified and therefore phase of the injury (acute vs. chronic) was not able to be assessed. This factor may be important for the emotional experience expression specific to the findings of this study.

Acknowledgements

Special thanks to the Unmasking Brain Injury Project for their advocacy work and willingness to share the stories of people with ABI. Thank you to the undergraduate research assistants for their contributions to this project.



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