

# The Story of Acquired Brain Injury:

A Mixed-Method Analysis of  
Autobiographical Narratives from  
ABI Survivors

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# Meet the Presenters



Amy Kemp



Olivia Vruwink



S. Kay Gregory



Katy O'Brien



# Disclosures

## Amy Kemp

- **Relevant Financial Relationships:** salaried postdoctoral fellowship with the Department of Veterans Affairs
- **Relevant Nonfinancial Relationships:** non-salaried postdoctoral scholar at Northwestern University and Social Media Lead on the Communications Committee for Academy of Neurological Communication Disorders and Sciences (ANCDs)

## S. Kay Gregory

- **Relevant Financial Relationships:** has no relevant financial relationships to disclose
- **Relevant Nonfinancial Relationships:** no relevant nonfinancial relationships to disclose

## Olivia Vruwink

- **Relevant Financial Relationships:** receives a stipend and tuition waiver as a PhD student at the University of Minnesota
- **Relevant Nonfinancial Relationships:** no relevant nonfinancial relationships to disclose

## Katy O'Brien

- **Relevant Financial Relationships:** salaried scientist with Courage Kenny Rehabilitation Institute and Allina Health
- **Relevant Nonfinancial Relationships:** past chair of the Brain Injury Association of Georgia



# Agenda

**01**

Introduction

**02**

Methods

**03**

Results

**04**

Conclusion





# Learning Outcomes



Understand the use of  
art-based approaches



Learn about the  
intersection of art,  
narratives, and  
health outcomes



Consider the  
implications for clinical  
assessment or  
treatment



Intro

ABI

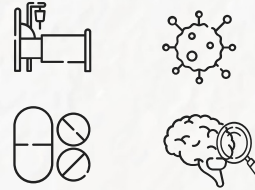


# Acquired Brain Injury



## Traumatic

Alteration in brain function, or other brain pathology, caused by an external force



## Non-traumatic

Damage to the brain by internal forces (lack of oxygen, exposure to toxins, pressure)



# Consequences of ABI



# Role of Art

Powerful modality that allows to convey their thoughts and emotions in visual and tangible form

Art-based methods can provide people with ABI the outlet to:

- Rely abstract concepts and emotions outside of words or beyond the linguistic abilities of a person
- Externalize their internal world
- Support coping and processing of emotional experiences related to their ABI

# Role of Storytelling

The experience of ABI are often associated with changes to identity, as well as navigating adaptations or modifications from the injury

Storytelling can provide people with ABI the outlet to:

- Process difficult experiences
- (Re)connect with peers, families, or communities
- Increase person-centered communication



# Dimensions of Wellness



(Hettler, 1978, 1976)

# How artists feel about Dimensions of Wellness



(Hettler, 1978, 1976)

# Unmasking Brain Injury



**Mission:** support people with ABI to create masks and write short narratives, so they can share and reflect on their experiences



# Origin of Unmasking Brain Injury Project





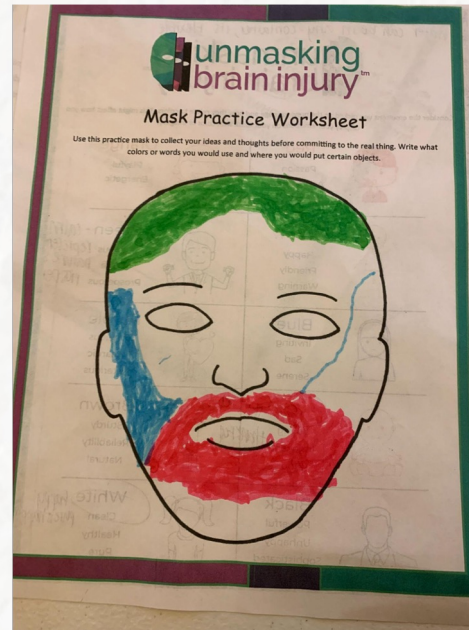
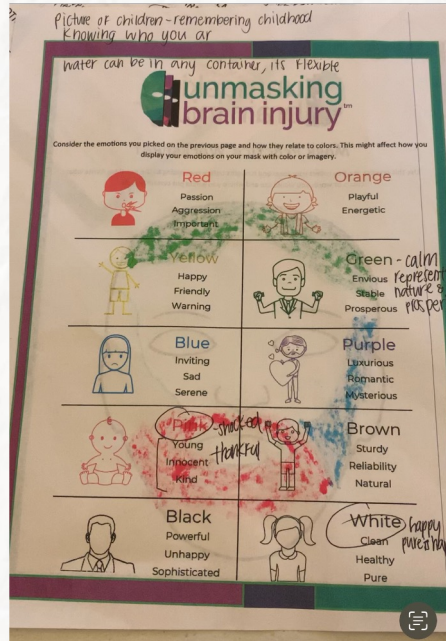
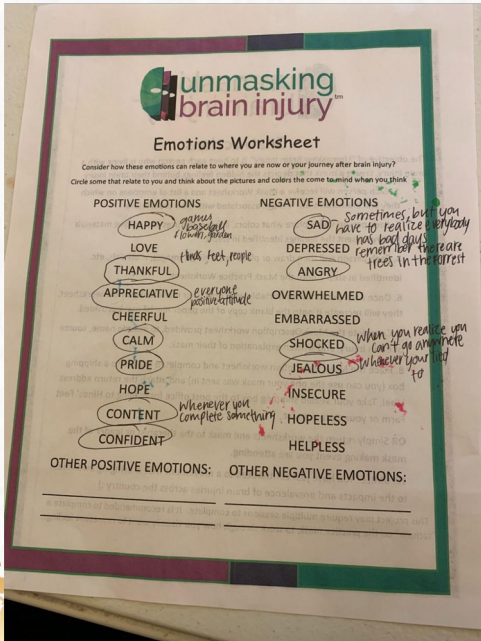
# Making a Mask

Identify emotions

Match to colors/  
objects

Practice

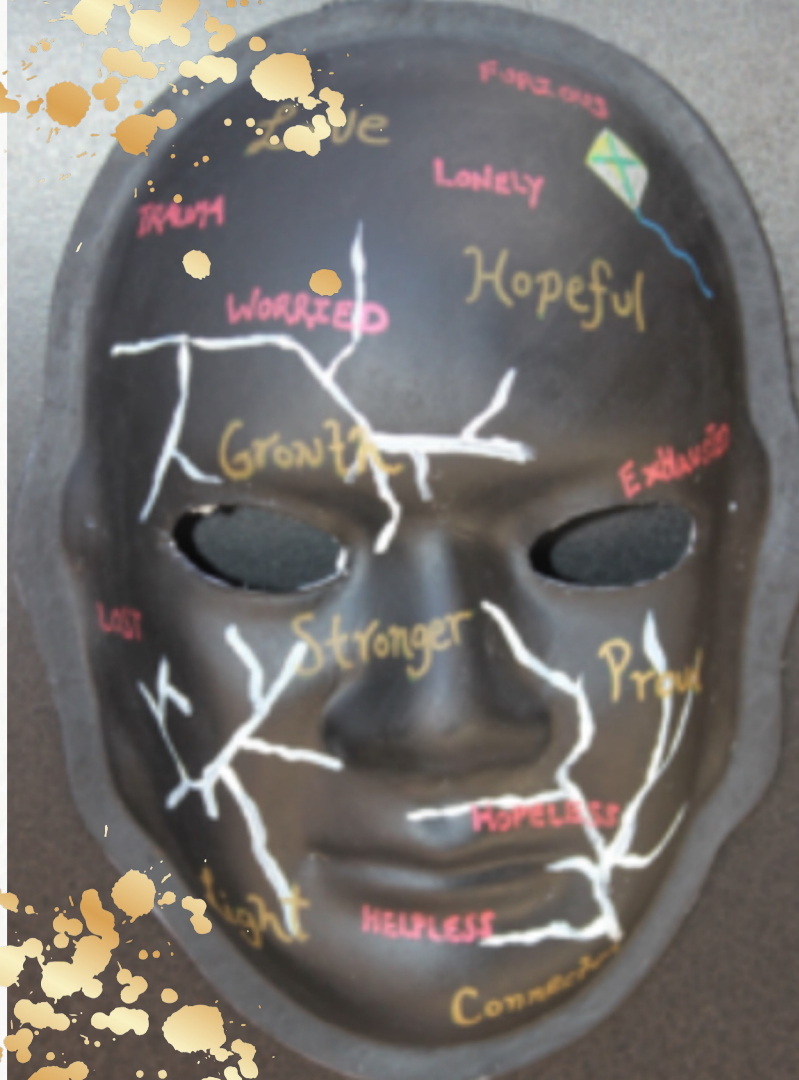
Make!





[Chelsea: feelings] [Matt] Feelings of shock



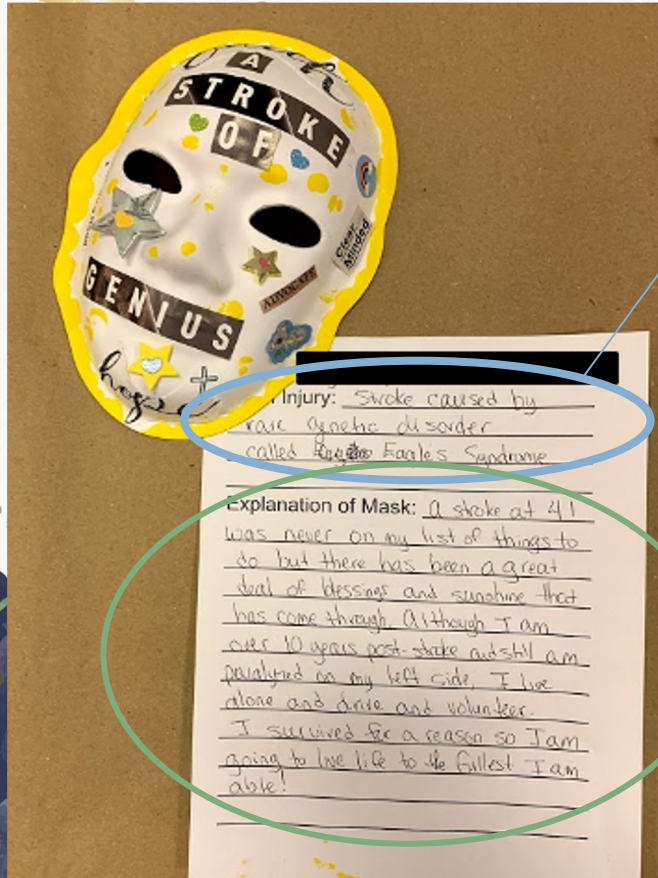


# Methods

## Mixed Methods

QUAL  
QUAL(quant)

# Data Collection



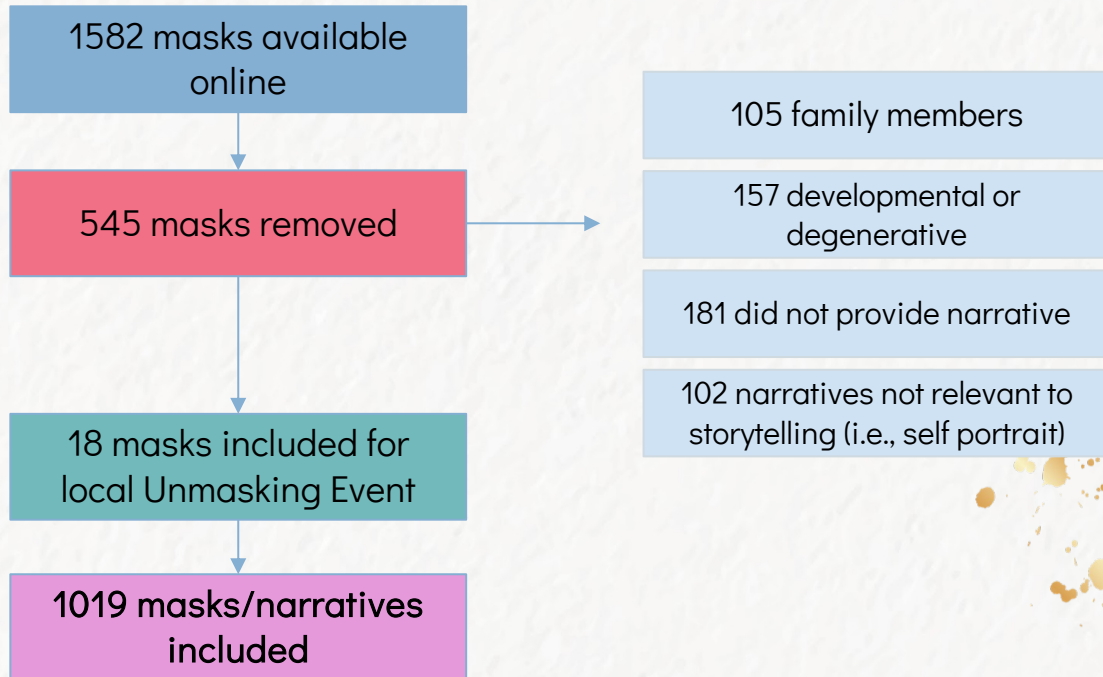
Injury mechanism coded

Injury: Stroke caused by rare genetic disorder called ~~the~~ Farley's Syndrome

Explanation of Mask: A stroke at 41 was never on my list of things to do but there has been a great deal of blessing and sunshine that has come through. Although I am over 10 years post-stroke and still am paralyzed on my left side, I live alone and drive and volunteer. I survived for a reason so I am going to live life to the fullest I am able!

Narratives/Art Matching

# Inclusion/Exclusion





# Art-based Analysis

## Data Mining

Masks/Narratives pulled from website (first screening)

## Narrative/Art Matching

Second Screening for content of narratives matching to art

## Inductive Coding

First 100 masks inductively coded; iterative process to create final product

## Thematic Analysis

Themes and subthemes grouped and quantitized for analysis of trends

# Wellness Analysis

## Phase 1: Storytelling Intention

Utilized grounded theory to inductively develop codes and themes

## Phase 2: Dimensions of Wellness

Used deductive coding based on Hettler's Dimensions of wellness

## Phase 3: Emotional Valence

Employed MAXQDA's natural language processing to determine each narrative's emotional valence

# Sentiment Analysis

Sentiment analysis (SA) is the task of extracting and analyzing people's opinions, sentiments, attitudes, perceptions, etc., toward different entities such as topics, products, and services.

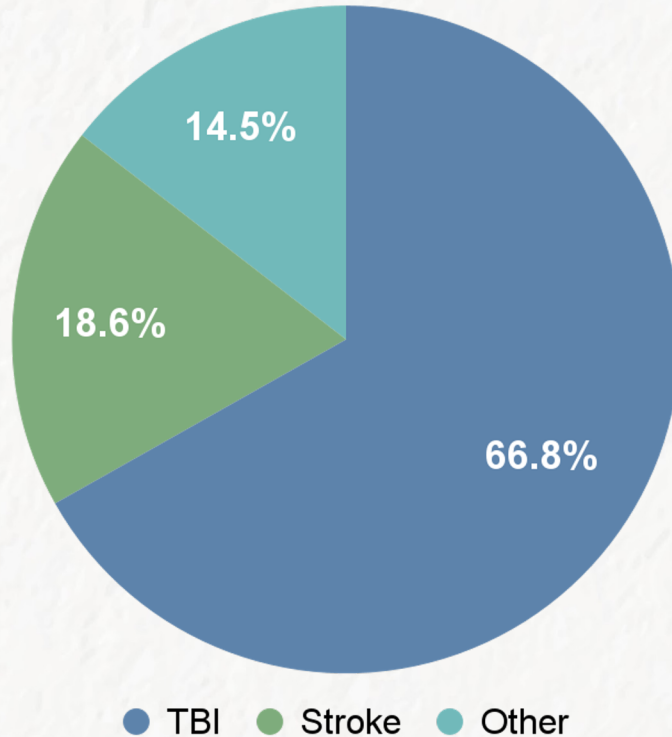




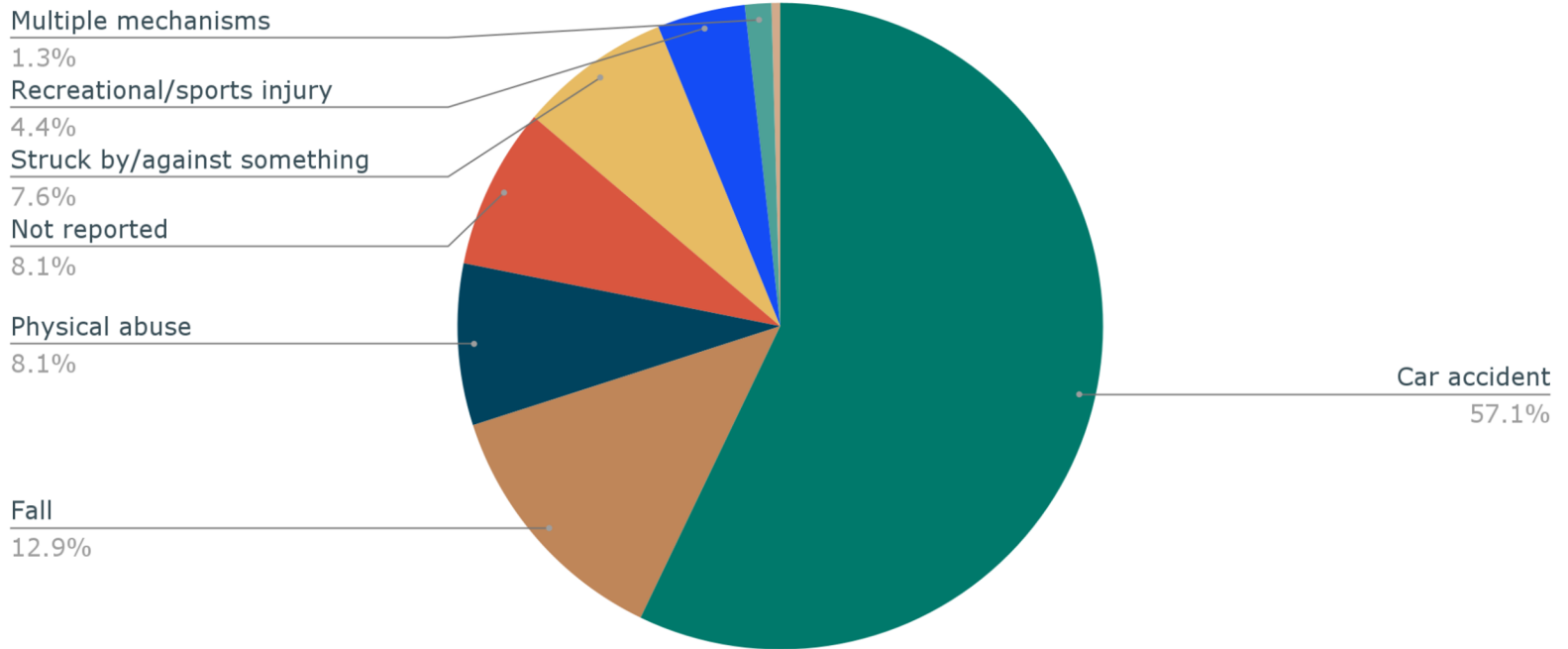
# Quality

- Initial coding completed by main authors to develop codebook, then by trained undergraduate research assistants
  - Inter-rater reliability was completed for 10% of data
    - 97-98% agreement
- Reflexive discussions to come to consensus
- Member checking by local brain injury group and HFF leaders

# Participants by ABI Type

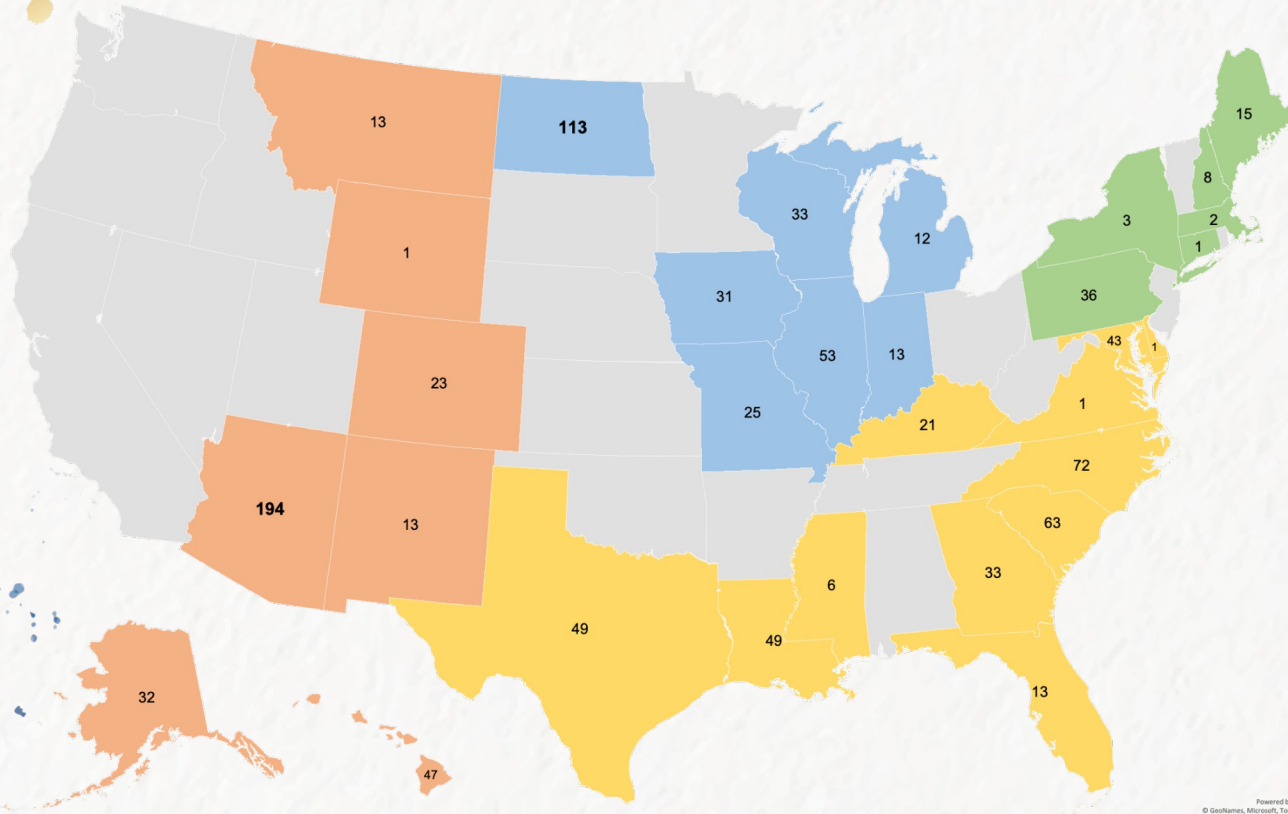


# Participants by TBI Injury Mechanism





# Participants by Geographic Location



Northeast	6.4%
Midwest	27.5%
South	34.4%
West	31.7%



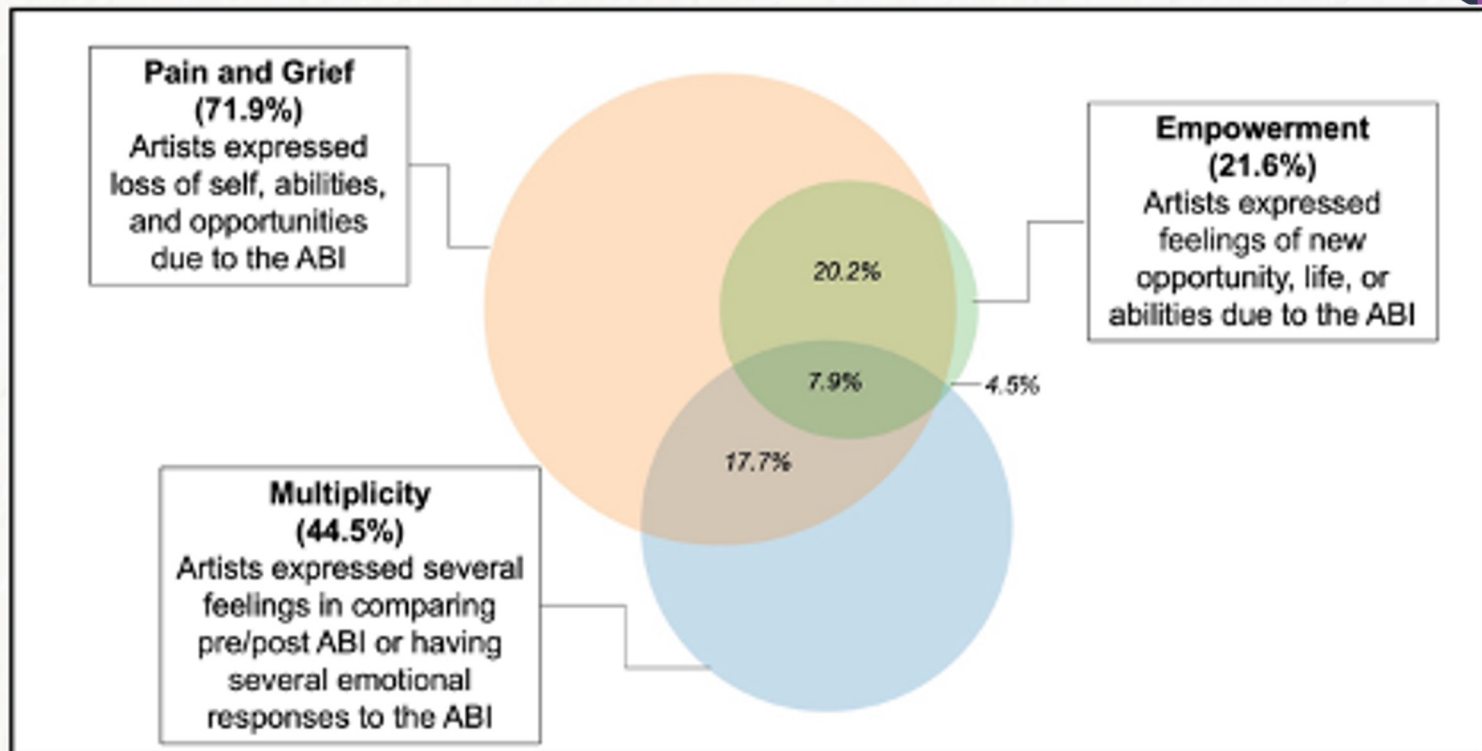
# Results






# Art-based Analysis







# Multiplicity





## **Theme 1: Multiplicity**



# Pain and Grief




**Theme 2:  
Pain/Grief**








# Empowerment

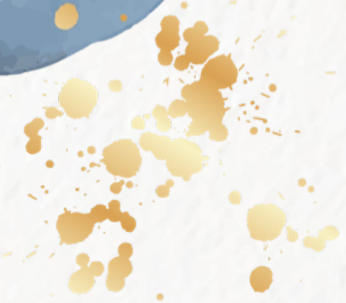
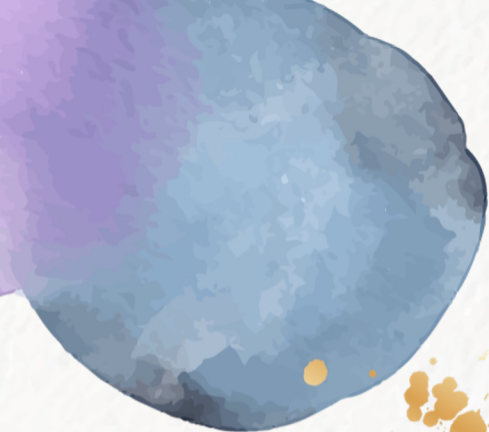


## **Theme 3: Empowerment**





# Wellness Analysis



# Phase 1

## Storytelling Intention



Storytelling  
Intention  
Document-level








**98%**  
**Outward**  
**Sharing**

- Rehab/Therapy
- Loss
- Changes
- Invisibility
- Faith



**74%**  
**Inward**  
**Reflection**

- Support
- Determination
- Acceptance
- Life Prior
- Journey

# Outward Sharing

“Even though all this is going on, I look like any other teenager. Looking normal and happy is not the same as feeling normal and happy.”

“When faced with adversity, we must seek guidance from our faith, have hope that all things are possible and rely on our inner strength, courage, and perseverance to finding a better day.”

- Changes (cognitive and physical)
- Faith (also hope, luck)
- Recovery (rehabilitation, healing)

# Inward Reflection

“Super “S” to represent how I feel everyday overcoming everything injury brings daily.”

“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.”

- Personal growth and acceptance
- Before and After
- Social Support





# Phase 2

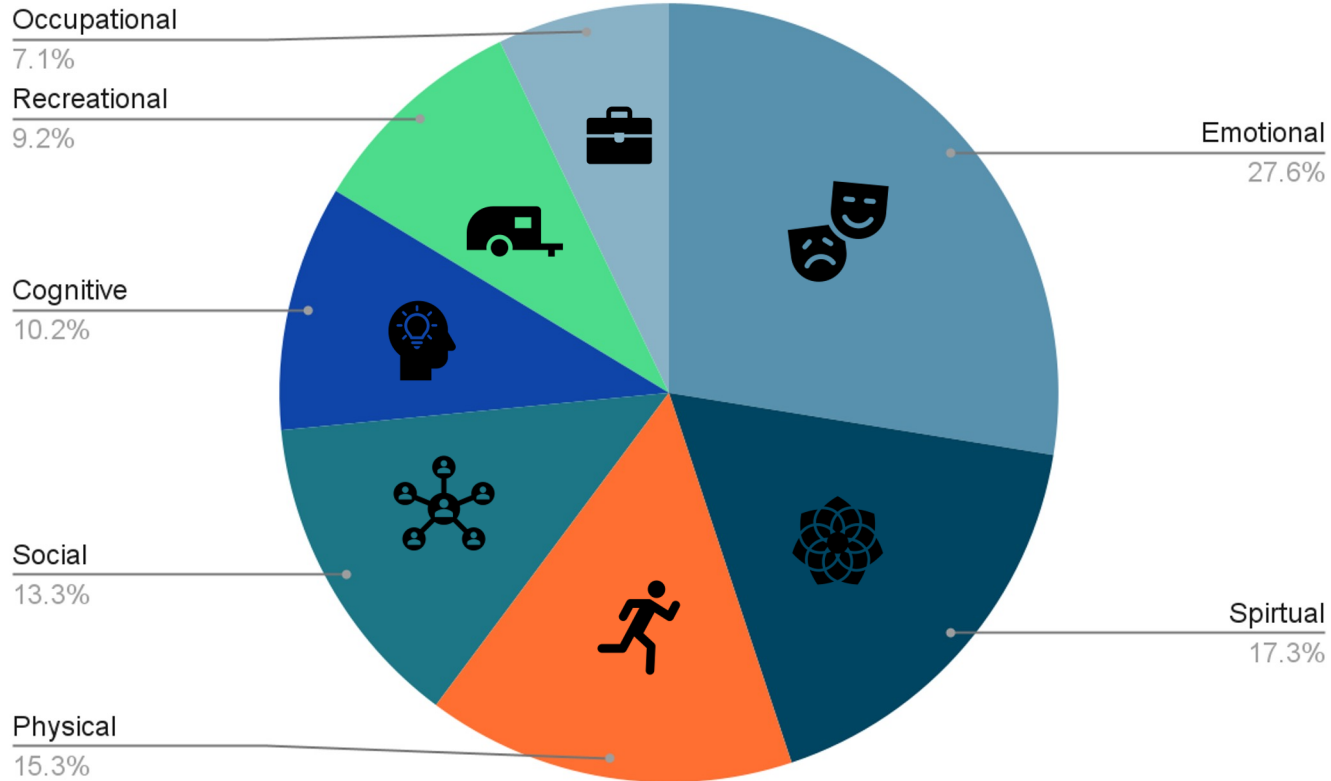
## Dimensions of Wellness

**Storytelling  
Intention**  
Document-level

**Dimensions of  
Wellness**  
Sentence Level



# Phase 2: Dimensions of Wellness





# Phase 3

## Emotional Valence





# Phase 3: Emotional Valence

## Positive

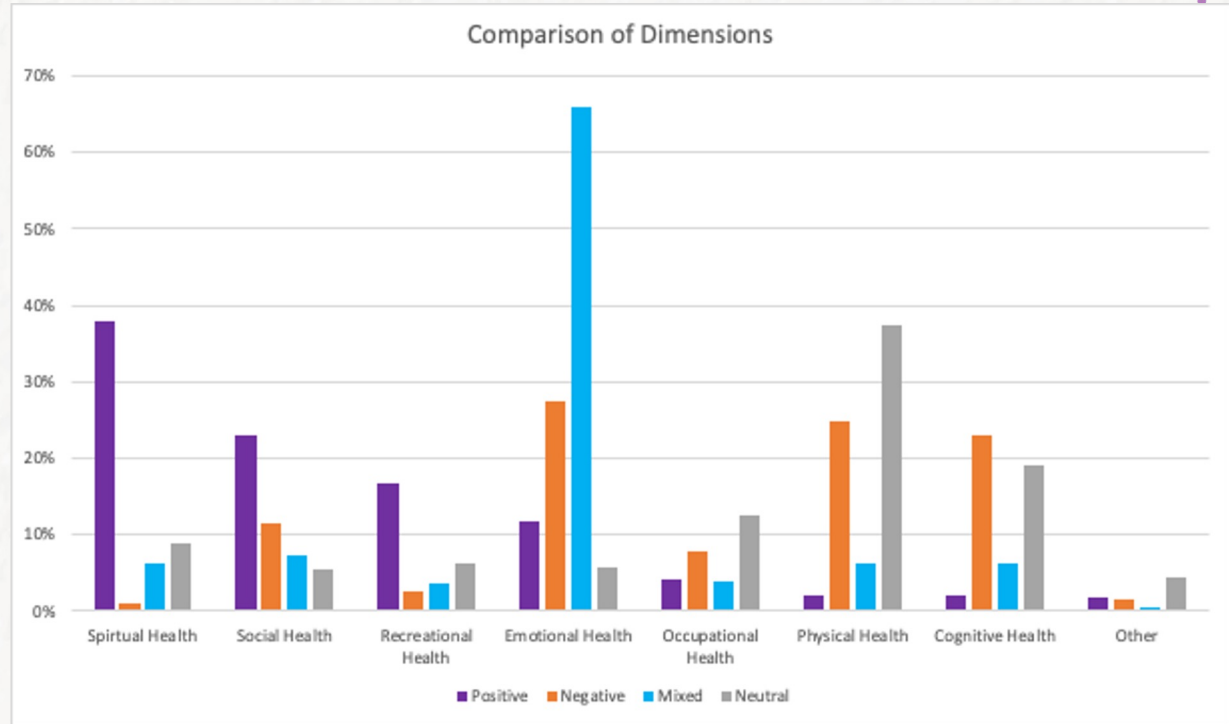
Spiritual, Social,  
Recreational, Emotional  
Health Domains


## Negative

Emotional, Cognitive,  
Physical Health Domains

## Mixed


Emotional Health  
Domain






I chose to use a HEART shape to connect the two masks to represent the BOND between caregivers and survivors, because both lives are greatly affected by TBI.”

## — Positive (social)



“The heart depicts my lost marriage due to my wife unwilling or unable to handle the changes in my life... The smile is for the fact that I am a survivor when no one thought I would survive, let alone recover.”

## — Mixed (emotional)



A big part of my identity was lost when I lost my memory and I am still struggling with feeling like a STRANGER TO MYSELF, that is represented by the puzzle pieces. Sometimes I feel like my whole identity is my brain and my brain injury, that is the exposed brain on my mask. I try to put on a brave face but I am really sad and depressed.”

## — Negative (social/emotional)





# Conclusions & Clinical Implications



# Art as a tool...

- **Art-based Methods**
  - Artists most prominently displayed feelings of pain/grief
  - Multiplicity demonstrates how artists are using the masks to explore the full experience after ABI
- **Expression**
  - Language/communication play a large role in engaging with others
  - Art may be supplemental to participate and communicate with others
    - Benefit with other narrative approaches and co-construction

# ...to share experiences and create goals

- **Outward Sharing**

- What changes after ABI (*cognitive, physical, emotional*)
- What does recovery look like (*cognitive, physical, emotional*)
- What might help someone with an ABI (*faith, recreational*)

- **Inward Reflection**

- What has changed FOR ME (*cognitive, physical, emotional*)
- Where am I now (*emotional*)
- What really helped ME (*faith, social support*)

# Therapeutic Alliance

- Building trust and connection is critical
  - Acknowledgement, respect, challenge, understand, encourage (Lawton et al., 2019)
- Part of holistic recovery and care
  - Improve quality of life and address all areas of wellness which lead to fuller and more meaningful lives



# Patient-Centered Care

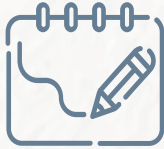
- Valued-living decreases significantly after TBI (Pais et al., 2019)
  - What outcomes and goals are important to the person with brain injury?
  - What do they find meaningful or important?
  - Important to consider the whole person
- Accessibility
  - Provides language support, emotional identification support, concrete/physical meaning to intangible feelings
- Meaningful participation
  - Identifying what matters to a person and offer a sense of purpose

# Coping and Processing

- Brain injury affects all areas of someone's life in different ways. How someone views themselves because of the ABI, the recovery, or the support is important to acknowledge where they might be and what might need more support.
- Art may be a method to make invisible injuries **visible and tractable**
  - Identify positive and negative areas of health
  - Track over time to show progress

# Future Directions

Art-based  
Methods



Addressing Coping  
and Processing



Highlight  
strengths/purpose





# Limitations



**Demographic  
Data**



**Injury  
Characteristics**



**Access to  
Unmasking Event**



**Election/Ability  
to create a mask**



# Thank You

To Hinds' Feet Farm (Chelsea Willis, Beth Callahan and Martin Foil) and ABI survivors (Matt, Allie, Beth, Danny, Eric, Klarc, Traci) who completed member checking, as well as shared their stories and art.

To Kelly Campbell, Roger Brathwaite, and Leslie Petsoff for warmly including us in Unmasking Events.

Thank you also to the CogComRehab Lab research assistants – Madison Wilson, Gabriella Wheeler, Autumn Knight, and Alexis Fowler– for the time and effort during this project.

# Questions?

- What thoughts do you have about using art-based methods in clinical practice?
- How could (or has) Unmasking Brain Injury be used in clinical practice?
- What else do art-based methods, such as making a mask, do for people with acquired brain injury?
- How will you use Unmasking in your own practice or your own recovery?



# Contact

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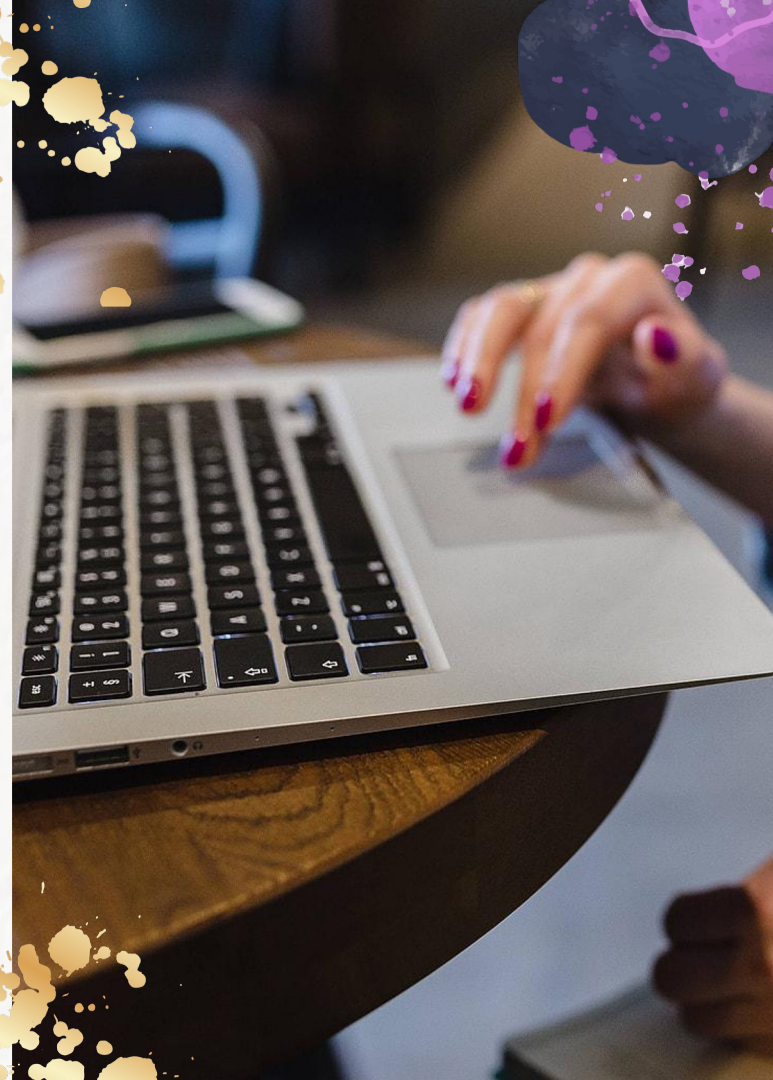
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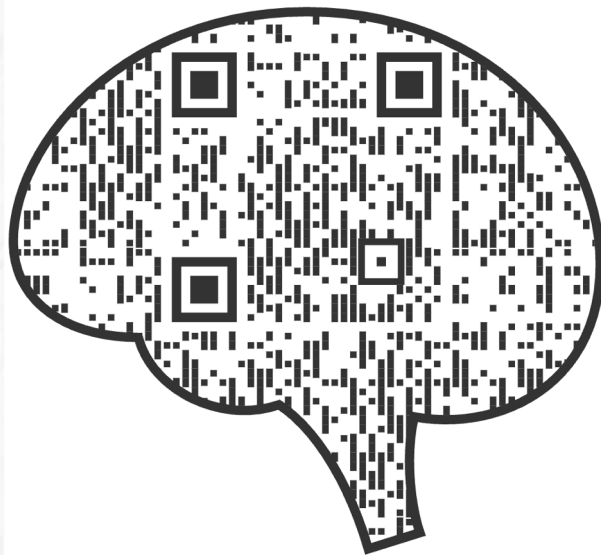
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# References







# Thanks!

Do you have any questions?

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