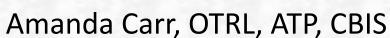
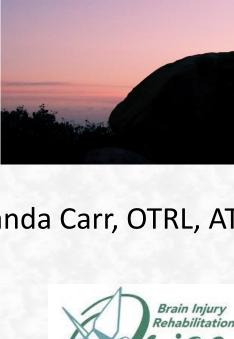
# The Power and Joy of Story

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#### Objectives

- 1. Understand the relationship between narrative, identity, and awareness.
- 2. Understand one method to co-construct personal narratives of rehabilitation journey.
- 3. Understand the impact of story construction process from participant perspectives
- 4. Question/Answers



## **Key Concepts**

- <u>Identity</u>: "Who we are, where we are coming from, and where we are going" (p. 36)
- <u>Personal Narrative</u>: Way for people to begin to put their lives together by reconstructing the past and imagining the future as an ongoing narrative that depicts who they were, are and will be<sup>2</sup>
- <u>Co-Construction</u>: collaborative act of assembling a story together<sup>3</sup>

## Identity, Narratives, and TBI

Identity is developed through language-based narratives<sup>2,3</sup>

TBI alters identity<sup>4,5,6</sup>

Model of Necessary steps to Fulfilling Meaningful Outcomes<sup>7</sup> Health professionals may play important role in using narratives to support identity<sup>3-6</sup>



<sup>9</sup>Neimeyer (2001); <sup>10</sup>Romanoff (2001)



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<sup>11</sup>Ruth & Kenyon (1996); <sup>5</sup>Fraas (2015)



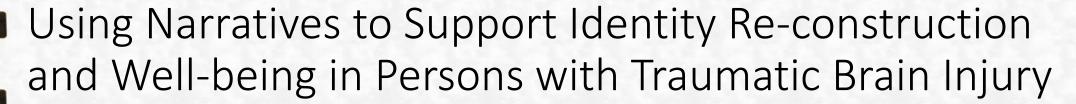
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<sup>11</sup>Ruth & Kenyon (1996); <sup>5</sup>Fraas (2015)



<sup>12</sup>McLean, Pasupathi, & Pals (2007); <sup>13</sup>Nochi (1997), <sup>14</sup>McAdams (2008);



- Self-identity after Brain Injury<sup>4</sup>
- Narrative Medicine<sup>5</sup>
  - Oral History Project<sup>5</sup>
- After Brain Injury: Telling Your Story, A Journaling Workbook



"I was uncomfortable going anywhere near home. I would go to places far from home where nobody knew me. I tried to mask everything and just tried to leave when someone saw me."

Leslie

Evening of Reflections Participant

# REFLECTIONS &

#### Dynamics of the Group

- Committee was comprised of 2 occupational therapists, 2 speech language pathologists, and receptionist
  - Client requirements:
    - Had completed or nearing completion of therapy
    - Balance of gender, funding source, ideology of injury
    - Who would benefit from this therapeutic process. They had to have some kind of emerging awareness to work on acceptance piece

#### Breakdown of the Process

- 7 months to prepare
- Monthly meetings as a large group; 1-2 hour meetings
- As needed 1:1 writing/practice sessions, small group practice each month

#### First Meeting

- What is E of R
- Why me?
- Watched past speeches
- How to Create your Story Handout

#### Meeting 2-7

- Meetings 2-4
  - Writing of their story in small groups (2-3 people) and receiving feedback
- Meetings 5-7
  - Story delivery and gathering feedback
  - Created a theme and voted on a Master of Ceremony
  - Determined order of speakers
  - Dress Rehearsal

#### **Know your Population**

- Change in Speakers
  - Approached higher functioning clients to join the group a little late (last add on was month 3)
  - Accurate and timely follow through
    - Constant reminders from the receptionist on upcoming meetings or 1:1 sessions
    - Offered assistance/guidance on where they were at in the process
    - Had back up copies of all speeches

#### Create Your Story Outline

- Give some background information about yourself
- When and how were you injured?
- Describe the problems and feelings you experienced immediately after your injury?
- What specific problems have you been working on in rehabilitation?
- Describe how the problems may have affected yourself and others.
- What progress have you made and how did the rehabilitation experience help you to make that progress?
- What progress have you observed in your level of awareness and understanding of brain injury?

#### Create Your Story Outline

- What progress have you observed in your ability to compensate and use strategies for remaining problems?
- What progress have you observed in your willingness to accept coaching/feedback from trusted others?
- Describe what you have come to accept about yourself
- What personal strengths have you discovered about yourself which has helped you and will continue to help you in rehabilitation?
- Special acknowledgment to family/friends/etc.

#### **Evolution of One Story**

- "I felt very awkward in social situations because I couldn't keep up with conversations or would simply forget what was being talked about."
- "I had tremendous Sensory overload and still to this day I sometimes wear ear plugs. I have to use lists for everything."
- "I now have a better understanding of the levels you go through after a TBI and that you cannot predict how you might act, but can understand what is happening."
- "My biggest asset from all of the coaching and feedback is learning to laugh at myself (which should have been easy because everyone else does) humor is the best medicine!!! I know when someone LOOKS at me like I'm crazy, I've either said or done "Something"."



#### Case Study

- First Meeting
- Triggered the need of a psychologist
- Specific plan on how to complete outline based on emotional tolerance
- Mass repetition in various settings

#### Evening of Reflections EVENT

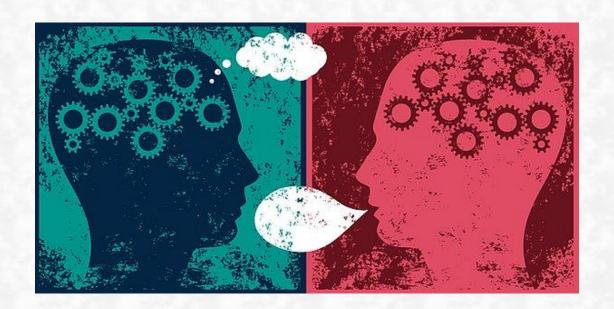
- Theme- "Through Acceptance, Faith, and Perseverance; a New Life"
- Master of Ceremony
- Roles and responsibilities that evening

## Case Study

• Jo's Story

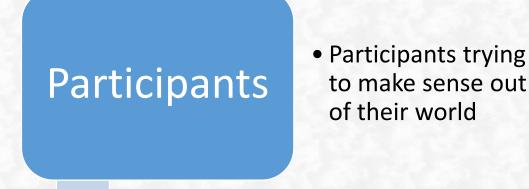
# Examining the narrative co-construction experience through a qualitative research lens

- Examining perspectives of the experience of coconstruction a personal narrative
  - Storytellers
  - Facilitators
- Project approved through CMU's institutional review board. Informed consent received for all participants.



## Study Design

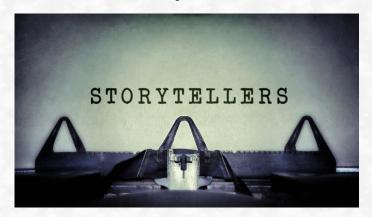
- Qualitative study using interpretative phenomenological analysis (IPA)<sup>16</sup>
  - 2-fold method of interpretation



Researcher

 Researcher then attempts to interpret participants' accounts of trying to make sense of their world

#### Participants



- 8 participants
  - 4 male, 4 female
- Age range 24-71
- Years s/p TBI 2-48
- Severity of TBI mild to severe
- Education, ranging from high school to doctorate



- 5 Origami rehabilitation staff
  - All female
  - 2 Occupational Therapists
  - 2 Speech-Language Pathologists
  - 1 Office Receptionist

#### **Data Sources**



#### **Storytellers**

- Individual interviews (45-90 minutes in length)
- Focus group with all 8 participants
- Pre-Post Behavioral Assessment of Dysexecutive Syndrome(BADS) Questionnaire

#### **Facilitators**

Focus group with all 5 facilitators

All interactions were videotaped. Videos were transcribed by 3 undergraduates, 1 graduate student, and Dr. Strong. Each transcript was reviewed three times to reliability.

#### 6-step Interpretative Phenomenological Analysis (IPA) Process<sup>17</sup>

• Reading and re-reading Initial noting • Developing emergent themes • Searching for connections across emergent themes Moving to the next case Looking for patterns across cases

# Key Findings

Storytellers

Facilitators

Recommendations

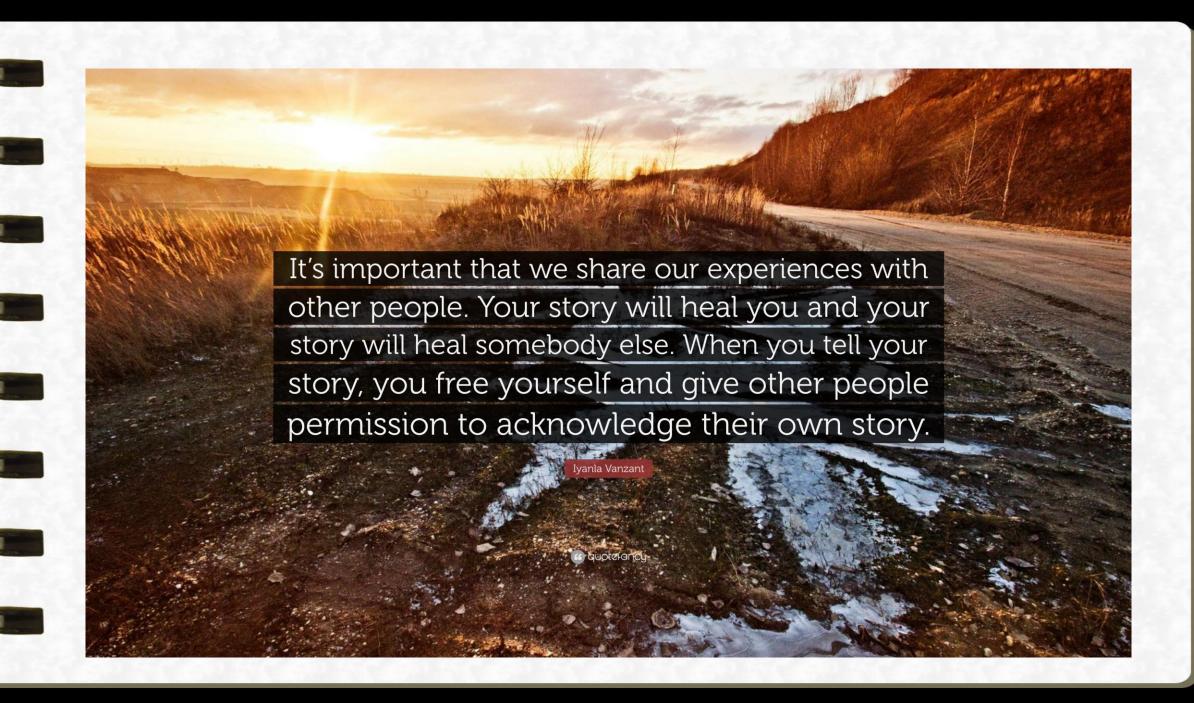


#### Clinicians' Attributes

- Counseling within your discipline/comfort level
  - Comfortable giving and receiving feedback
- Flexibility- viewing things in alternative ways
- Intuitive
- Guidance
- Prepared for the journey

#### Quality Improvement

- Different Assessment Tool
- More purposeful with imbedding their goals of looking towards the future
- Being purposeful with the 3 steps
  - Narrative
  - Identity
  - Co-Construction
- Incorporating into daily treatment
- Impact of participants' viewing their video presentation
  - Video tape feedback prior to the public event



# Using narratives to support persons with TBI



#### **Survivors and Caregivers**

- Do you have a story developed to share with others?
  - If so, how did you develop your story?
  - What format is your story in?
    - Pictures, written, talking, video
  - What environment have you shared it in?
    - One on one vs. large group, formal vs. informal

#### **Clinicians**

- Do you use stories in your work?
  - If so, what methods or process have you used?
  - If not, can you see a way to incorporate narratives into your practice?
- What resources do you have to share?

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# To continue the dialogue on narratives, identity, and TBI please contact



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