TBI and Identity Loss:
Recovering Self

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Disclosure Statement

My only disclosure is that I am an employee of Brookhaven Hospital in Tulsa, Oklahoma. The content of this presentation is designed to promote quality improvements in healthcare and not advocate for any particular provider or entity. In addition, every effort has been made for the information to well balanced, evidence based and unbiased.
Overview

1. Developed from psychotherapy perspective.
2. Concepts generalize to other professions (e.g., OT, SL, PT).
3. Challenges all to work toward optimal outcomes.

“I knew my “self” and my role in life had changed and I would have to accept it and adapt.”
Today’s Goals

LEARN

About identity change after traumatic or acquired brain injury.
Today’s Goals

REVIEW

Seminal research on concepts related to identity loss
Today’s Goals

LEARN

Three models of disability identity after brain injury
UNDERSTAND

Difference between an adjusted vs. a self-examined life post injury
LEARN

Today’s Goals

How to find personal meaning in life after brain injury
Identity: persons’ conception and expression of their individuality or group affiliation
Self-concept: the sum of a being’s knowledge and understanding of self.
Sarah’s Storm
The Car Wreck
The Symptoms

Depressed
Anxious
Lack of Concentration
Unable to Work
Relationships
Suffer
Work Suffers
Sleep Suffers
Divorce
Diagnosis: PTSD
WHAT ARE THE DAMAGED BRANCHES?
Ambiguity & Uncertainty
Stranger in Relationships

DAMAGED BRANCHES
TBI Creates Uncertainty and Stress
Walking on Eggshells

DAMAGED BRANCHES
What About Identity Loss?
Loss of Self
Long-term physical, cognitive and emotional problems accompany brain injury
Ambiguous loss is most stressful & defies closure
Self uncertainty correlates with perceptions of boundary uncertainty with others
Manifests as identity uncertainty
Client may develop a profound “loss of self”
Three Categories of Loss
(Nochi, 1998)

Loss of clear self-knowledge

• Memory loss effects
• Lack understanding of reason for situation
• Uncertainty of where “I” come from
• Terrified of all the blanks

“I struggle daily to do my job and be the person I used to be. I still, after two years, am trying to redefine myself. I don’t know this person anymore. She is not reliable and cannot be trusted as my best friend.” --Alienation from self
Three Categories of Loss
(Nochi, 1998)

Loss of self by comparison

• Usually compare with pre-injury self
• Compare self with what they are AND
• What they would have been--
• The loss of INDIVIDUAL POTENTIAL

“After the accident…my son was three years old, and I knew he was my son. But the feeling like we were connected was gone. He was a total stand alone person. I’d always felt like we were somehow, like there was a magic chord from me to him. It was gone right after the accident.”
Three Categories of Loss
(Nochi, 1998)

Loss of self in the eyes of others

- Believe others think less of them
- Others put a negative level on them
- Individuality is obscured by labels

“I don’t like the term TBI because it just puts another stigma. It puts things on people. Suppose I say I have a TBI, and that’s going to stop people from getting to know me.”
“Imagine waking up each day with a pounding headache, always feeling like you have a hangover plus a bad flu after being up three nights in a row; having trouble concentrating, remembering, and getting your thoughts together; losing your temper and snapping at people for no reason. On top of that, nobody believes you or thinks you are crazy.”

Examined writings of those with disability to identify illustrations of their disability identity.
Dunn, D. & Burcaw, S. (2013)

Disability Identity can focus on:

Past: what once was.

Present: what is still true.

Future: our wishes, expectations and fears.
Consider Disability Identity on a Continuum

Disability identity may or may not be activated.

By definition, professional services activate the identity.
Dunn, D. & Burcaw, S. (2013)

Three Categories on the Continuum

1. Individual with some functional limitations & may identify self as disabled or not.
2. Disability rights activists focus on social constructs and civil rights.
3. Disabled identity is tied to self-concept…
   a) Positive
   b) Negative
   c) Ambivalent
Negative and Ambivalent Consist of Two Groups

**Coping**
- Emphasize assets vs. fixing what’s broken
- Focus on skills
- Set goals

**Succumbing**
- Mask disability
- Seek impossible standards
- Emphasize deficits

Creating Self
Dunn, D. & Burcaw, S. (2013)

One Key

Finding Personal Meaning Post Injury

- Significance in Life
- Goal Setting
- Engaging in Sense Making
- Finding Benefits Associated with Injury
Dunn, D. & Burcaw, S. (2013)

Significance in Life
Goal Setting
Engaging in Sense Making
Finding Benefits Associated with Injury

Important Aspects of Identity and
Becomes a Form of Acceptance

“We judge ourselves by what we feel capable of doing, while others judge us by what we have already done.”

Henry Wadsworth Longfellow
What About other Research?
“Am Not Was”
Dewar & Gracey (2007)

Case study of symptoms of identity loss of person suffering from herpes simplex encephalitis.
“Am Not Was”
Dewar & Gracey (2007)

The Symptoms

- Anxious
- Loss of Interest
- Hopelessness about Future
- Unable to Work

- Limitations in Fulfilling Role
- Decreased Social Contact
- Fear of Not Recognizing Others
“Am Not Was”
Dewar & Gracey (2007)

Her Identity

“If I can’t remember my friends, then I am a bad, uncaring person.

“If I don’t do things for my children, then I’m a bad mother.”
“Am Not Was”
Dewar & Gracey (2007)

What Are the Trigger Situations?

- Failing to Recognize Someone
- Others Doing Things for Her
- Family Not Getting Along
- Family Efforts to Reassure
- Family Taking on Tasks
“Am Not Was”
Dewar & Gracey (2007)

Interventions
Standard CBT

- Rapport building
- Self-monitoring
- Identify negative thoughts
- Breathing techniques
- Decrease anxiety
“Am Not Was” Dewar & Gracey (2007)

Interventions

Behavioral Experiments

• Positive experiential learning
• Complete 75% of role tasks
• Relearn autobiographical memory
• Face recognition
• Shared understanding with family to not threaten identity
“Am Not Was”
Dewar & Gracey (2007)

Outcomes

Increase in Self-ratings of Pre-injury vs. Current Self

Increase in Self-esteem
How we create a new realistic outlook?
The Premise

C.G. Jung: “The soul of man seeks Meaning or Purpose for its existence.”

Prigatano, G. (1991)
The Premises

1. In life transitions, people wonder about the meaning of their life.
2. Brain injury produces an abrupt transition in life.
3. Individuals ask, “Will I be normal,” Why did this happen to me?” “Is life worth living after brain injury?”
4. Traditional psychotherapy (or others) cannot answer these.
5. They are existential and only by entering the experience of the patient are the questions answerable.
6. Thus, rehabilitation and psychotherapy must focus on the disordered mind and wounded soul.

Prigatano, G. (1991)
Understanding the Patient

Unfortunately we understand the patient in relation to diagnoses, behavior and billing codes.

“Understand the mind of the patient and rehabilitation goes more smoothly.”

Prigatano, G. (1991)
Understanding the Patient

- Understanding of patient reluctance
- Strike balance with the Medical Model
- “Get in to” the patient’s world
- Facilitate engagement in the rehabilitation process
- Juxtaposed to our “silo services” method
- Applicable to all disciplines

Prigatano, G. (1991)
Focus on the Soul

Therapy is a process of “teaching the patient to learn to behave in his/her own best self-interest.”

Focus on “discovering the meaning of their lives in the face of, not despite, the brain injury.”

Prigatano, G. (1991)
Psycho (and other) therapy
After Brain Injury

Help the Patient To:

• Understand the impact of brain injury and commitments they can still make.
• Know the impaired self-awareness interaction of the injury damage and the premorbid self.
• Guide, not force, to make decisions in their own best interest…Autonomy.
• Do not overwhelm with information (defined by diagnoses and billing codes).
• Focus on restoring the shattered sense of identity.

Prigatano, G. (1991)
Prigatano (1991) asserts:

Three symbols in our culture that “promise” meaning in our life:

- Intelligence
- Beauty
- Winning is Everything
Prigatano (1991) asserts:

Juxtaposed to other symbols that actually generate meaning:

- Work
- Love
- Play

Therefore, access music, humor, art, literature, exercise, spirituality and INDIVIDUAL STORIES or NARRATIVES as a part of the therapeutic process.
The Challenge

How do we incorporate these concepts in our service provision?

Where do we start?
The Therapist’s Role
Provide patience, sensitivity, and objectivity as the foundation.
Client’s perceptions of the deficits
Work toward better self-observation
Use reality-focused methods to address lack of awareness rather than direct confrontation.
Anticipate feelings of frustration, being overwhelmed, family difficulty and withdrawal from interpersonal relationships.
Emotional reactions such as depression, anxiety, flat affect, apathy, heightened emotions and even chemical dependency issues.
Engage the client and family as active participants.
Encourage to resume normal activities and assist in restoring the client’s diminished power.
Therapist frustration as our own expectations of recovery are not realized.
Awareness of and sensitive to counter transference issues from self.

Poses the question:

“Does attainment of optimal outcomes following neurorehabilitation require that the individual achieve an “examined self?”

Why is “examined self” important?

“To feel healthy again, assist in regaining (New) individual personality components so the person can accept voluntarily the limitations the brain injury imposes”…AND…

“Assist the individual to value their rehabilitation achievements and view their present life as meaningful.”

Ego Identity Components
(Evolving aspects of personhood, Erickson, 1950)

1. Identity as imitation
2. Identity as a sense of continuity
3. Identity as self-definition
Wellness Components

1. Autonomy
2. Environmental Mastery
3. Personal Growth
4. Positive Relationships
5. Purpose in Life
6. Self-acceptance

Rating Schema of Acceptance

1. Cessation of “mourning” or agitation over incurred losses—speak calmly about injury.
2. Morale—able to maintain cheerful & optimistic outlook on future.
5. Restored self-esteem—asserts SE has been restored.

Two Groups

Adjusted—those who, after treatment, responded well to intervention but showed no signs of re-defining themselves.

Self-examined—those who, after treatment, reflected upon their “self” and arrived at a subjectively satisfying self-definition.
“Does optimal outcomes following neurorehabilitation require that the individual achieve “examined self”. 

YES!

The Value?

The individual exhibits an increased sense of new personhood, maximizes their rehabilitation potential and overall satisfaction.

Seven adults interviewed who are experiencing autobiographical memory impairments were interviewed to see how their narratives and sense of self had changed after neurotrauma and how individuals attempt to regain the lost sense of self.

Types of Narratives

1. **Restitution stories** indicate illness will not interfere with previous plans and former selves will be restored in the future.
2. **Chaos narratives** have little order and makes it difficult to reflect on their illness experience.
3. **Quest stories** in which people claim their illness has produced a new identity.
Identity Construction is an Ongoing Narrative

Strategies individuals use to create a current self

1. Memory importation—transplanting memories from before the injury.
2. Memory appropriation—taking another’s memory as their own.
3. Memory compensation—conversationally compensating for missing memories.

Help the individual sustain personal narratives in the absence of autobiographical memory.
The self is not something that one finds. It is something that one creates.
“Clinical professionals need a better understanding of how people make sense of themselves, especially under extreme circumstances, before reaffirming or reconstructing a putatively damaged “self” in people whom the only thing we know is that they have a damaged brain.”


Qualitative study of 12 individual’s narratives.

What Did the Narratives Reveal?

1. Insulting and exhausting to be checked constantly.

2. Afraid of the power authorities had over their lives.

3. Hurt if others don’t believe in their opportunities.
What did they search for in a rehabilitation professional?

- One who listened to them.
- One who respected their goals.
- One who showed an understanding of their situation.

What Did They Describe As

Think positively
Trust one’s possibilities
Hate to give up

Have a strong will
Have hope
Manage feelings of shame & dignity
Self awareness is the capacity to recognize your own feelings, behaviors and characteristics - to understand your cognitive, physical and emotional self. At a basic level, it is simply understanding that you are a separate entity from others.

In a broader sense, the questions, 'Who am I?,' 'What do I want?,' 'What do I think?' and 'How do I feel (physically and emotionally)ettings that require self awareness to answer.
The Physician’s Story
'How could I continue to live with a deficient brain? My head injury had been bearable only because it was temporary. Permanent injury meant I had already lost. My job, my identity, my life, the real me.'
Medley, et. al. (2010). Brain Injury Beliefs, Self-awareness and Coping: A Preliminary Cluster Analytic Study Based Within the Self-regulatory Model.

Study to determine if the Self-regulatory Model can identify different clusters of subjective beliefs, coping styles and self-awareness with notion that understanding the interplay will prove more useful in rehabilitation…. than addressing the factors in isolation.
Maximizing the therapeutic relationship requires looking beyond client’s (or therapist’s) perceptions of injury on day to day functioning.
Other Factors to Consider

1. Client’s expectations about duration of symptoms.
2. Client’s perception about how symptoms might be managed.
3. How client makes sense of and copes with seemingly bizarre cognitive changes.
Medley, et. al. (2010) Cluster Analysis

Most Importantly

Considering their interaction might better inform the clinician of the individual’s rehabilitation goals.
Medley, et. al. (2010) Cluster Analysis

The Self-Regulatory Model

Posits that clients use multiple sources of information that converge to inform their beliefs and perceptions of a health threat (the brain injury) thereby influencing engagement and outcome.

- Internal: somatic experiences and personality
- External: information from health professionals and social interactions
The internal and external sources in turn determine the selection of coping strategies and influence outcomes such as engagement in treatment and psychological well-being.
Medley, et. al. (2010) Cluster Analysis

The Self-Regulatory Model
Five Core Dimensions

1. **Identity**: degree to which symptoms are experienced and attributed to the condition.
2. **Cause**: attributions for the condition.
3. **Time-line**: perceived duration of the condition.
4. **Consequences**: perceived impact on quality of life.
5. **Controllability**: beliefs about control and associated problems.
The Illness Perception Questionnaire-Revised
Nine Sub-scales Represent Perceptions

1. **Identity**: rate if have experienced symptom
2. **Cause**: attributions for the condition.
3. **Time-line**: perceived acute or chronic.
4. **Consequences**: on quality of life.
5. **Personal Control**: beliefs about personal control over the condition.
6. **Treatment Control**: beliefs about personal control and efficacy.
7. **Changeability**: unpredictability of symptoms
8. **Coherence**: understanding of condition
9. **Emotional Representations**: negative/positive
Medley, et. al. (2010) Cluster Analysis

Rehabilitation Engagement—Two Phases

**Motivational Phase**—beliefs and attitudes toward rehabilitation generate intention.

**Volitional Phase**—cognitive and executive functioning influence degree of active and sustained participation.
Medley, et. al. (2010) Cluster Analysis

Three Clusters Identified

Low Control/Ambivalent—Characteristics

- Ambivalent in attempt to preserve identity
- Lack coherent understanding of injury
- Recognize chronic duration
- Reported limited symptoms & issues with quality of life
- Reduced degree of self-awareness
- Defensive denial (more assault injuries)
- More avoidance coping
Medley, et. al. (2010) Cluster Analysis

Three Clusters Identified

High Optimism—Characteristics

- Decreased self-awareness
- Lower perception of chronicity
- Lower perception of consequences
- High perceived controllability
- More coherent understanding of injury
- Less avoidance coping
- More problem focused coping
Medley, et. al. (2010) Cluster Analysis

Three Clusters Identified

High Salience—Characteristics

• Experience & attribute symptoms to condition
• Highest level of coping strategies
• Recognizes consequence of injury
• High perceived personal & treatment control
• Greater use of problem focused coping
• Greater emotional processing
• Higher level of treatment adherence
What Do the Results Have To Do with Identity Recovery?

Emphasizes the clinical notion that every discipline would be prudent in striving for a more coherent understanding of the person’s “self” rather than staying in our own “silo”.
Overview

- Speaks to the loss of a sense of self in brain injury.
- Provides theoretical constructs related to denial.
- Offers overview of Relational Frame Theory.
- Advocates the use of Acceptance and Commitment Therapy as one avenue to recovering “self as context.”

Relational Frame Theory

- Developed within the field of behavior analysis
- An account of language and cognition
- Consists of ability to derive novel stimulus relations, without training, among events
- In short, responding to one event in relation to another (If A then B, conversely, If B then A)

Example: from car wreck, person derives relations between the event and private experiences e.g., anxiety, fear or flashbacks

Relational Frame Theory

Three Distinct Senses of Self Available to Us

2. Self as an Ongoing Process of Verbal Knowledge
3. Self as Context
Relational Frame Theory

Conceptualized Self

• Network of verbal self-relations that develops from our experiences
• Means of evaluating, explaining and predicting our own behavior
• We expect congruence between what we say we are and social feedback
• If not, we defend or distort our experiences of the world

Relational Frame Theory

Self as Ongoing Process of Verbal Knowing
(Ongoing Self-awareness)

- What a person may verbally know
- Consists of our thoughts, emotions, memories and private experiences
- In essence, comprises our psychological content
- If unable to discriminate and label, we have decreased self-awareness

Relational Frame Theory

Self as Context

• Necessary to report events in coherent manner
• Provides a sense of perspective, unique point of view
• Place from which the person experiences the world
• Is the "I" behind the eyes
• Safe place from which to know
• Never changes and never lost—locked in?

Relational Frame Theory

Conceptualized Self Dominates Self as Context

Brain Injury:
A Crisis of the Conceptualized Self

Loss of sense of self as a verbal (relational) process

“I am not the same person.”

Relational Frame Theory

Crisis of the Conceptualized Self

Awareness of inconsistency between pre-injury concepts and post-injury functioning

Me

Competent

Creative

Professional

Hard Worker

Team Player

Relational Frame Theory

Crisis of the Conceptualized Self

Awareness of inconsistency between pre-injury concepts and post-injury functioning

Incompetent
Uncreative
Unprofessional
Lazy
Not Team Player

Me

Relational Frame Theory

Conceptualized Self

Brain Injury

Crisis of Conceptualized Self

Denial

Relational Frame Theory

Denial

Understood as Protection of the Conceptualized Self

Relational Frame Theory

Denial

Unworkable for Two Reasons

1. Individual turns to avoidance.

2. Efforts to avoid increase emotional distress.

Relational Frame Theory

The Workable Alternative—Acceptance

Develop Self as an Ongoing Process of Verbal Knowledge

Develop Acceptance, Not for Its Own Sake

Develop Acceptance as It is More Workable Than Avoidance

Relational Frame Theory

Acceptance Through Self as Context

- Not based on psychological content—the conceptualized self.
- Not comprised of emotions, thoughts or private experiences.
- Is the place from which they are known.
- Make experiential contact—mindfulness.

Relational Frame Theory

Acceptance Through Self as Context

• Individual can know psychological content
• Alleviates fear of psychological annihilation
• Interact with content in non literal way
• Experience content as ongoing verbal relations vs. “facts”
• RFT is the basis for ACT

Acceptance and Commitment Therapy (ACT)

Treatment Approach for Experiential Avoidance

Guides Client to Contact Self as Context

Facilitates Acceptance

Acceptance and Commitment Therapy

Views the core of problems as FEAR

Fusion with your thoughts
Evaluation of experience
Avoidance of your experience
Reason-giving for your behavior

Wikipedia (2014)
Acceptance and Commitment Therapy

Views the core of problems as FEAR

“Train yourself to let go of everything you fear to lose.”
Yoda

Wikipedia (2014)
Acceptance and Commitment Therapy

The healthy alternative is to ACT

Accept your reactions and be present
Choose a valued direction
Take action

Wikipedia (2014)
Acceptance and Commitment Therapy

Core Principles

1. **Cognitive Defusion**: Learning methods to reduce tendency to reify thoughts, images, emotions and memories.
2. **Acceptance**: Allowing thoughts to come and go without struggling with them.
3. **Contact with the Present Moment**: Awareness of the here and now, experienced with openness, interest and receptiveness.
4. **Observing the Self**: Accessing a transcendent sense of self, a continuity of consciousness which is unchanging.
5. **Values**: Discovering what is most important to the one’s true self.
6. **Committed Action**: Setting goals according to values and carrying them out responsibly.
Acceptance and Commitment Therapy

Two Methods

1. Metaphors for abstract thinking
   - The House and Furniture
   - Chessboard

2. Experiential Exercises
   - The "Observer" Exercise

Acceptance and Commitment Therapy

Example

- Client experienced intense anxiety post injury
- Conceptualized as defense of pre-injury self-concept
- Guidance to accept new post-injury self-concept
- Allowed for pursuit of key life values—

The New Self and Purpose in Life

CLIENT’S VIEW OF INDIVIDUAL THERAPY
“It made me feel normal. I wasn’t crazy, I was brain injured. My therapist helped me understand that everyone’s healing process is different. She helped me understand the importance of not over extending myself. She made me feel safe.”
A Real Life Example
30 Minutes January 11, 2015
“Conquering the Impossible”

• Three Veterans Returning from Iraq or Afghanistan
• IED and Double Amputee with Likely Brain Injury
• They Enter The Heroes Project
• The Seven Summits
• Their Work to Reestablish Their Identity and Self-Concept
“Going through my injury, I lost myself. Didn’t have a clue who I was.”
Reaching the Summit

“Grrrr..ahhhhhh…”
“Something that you can carry with you the rest of your life and also helps you put closure on a period in your life too.”
“This injury like does not define my life, I define it. And life is still able to be powerfully lived even in this condition.”
TBI and Identity Loss: Recovering Self

Thank you!

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Questions?

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