Loss of self following brain injury: the task of building a new identity

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After more than a century of looking for it, brain researchers have long since concluded that there is no conceivable place for a self to be located in the physical brain, and that it simply does not exist.

TIME MAGAZINE
“How could I 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.”
Objectives:
Understanding the cumulative process of loss and bereavement
Assessing the components related to the changes in perception and value of self
Examining the relationship losses experienced by the person
Defining the post-injury experience
Ambiguous loss creates stress and defies closure
Uncertainty about self
The erosion of sense of competency and self worth
Struggling with issues of post-injury identity
Three categories of loss

Nochi, 1998
Loss of clear self knowledge
Loss of self by comparison
Loss of self in the eyes of others
“....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...”
Injury created barriers affecting the person
Loss of one’s sense of competency
Loss of previously learned skills
Loss of life focus
Becoming dependent on others
Experiencing changes in relationships
The challenges of relearning
Emotional response to loss
View of self living with an altered brain
Cognitive changes
Emotional changes
Behavioral changes
Reduced coping skills
Physical changes
Loss of self

Perception of self worth

Process of disengagement
Loss of social capital

Disengagement from naturally occurring social units


Christakis C, Fowler J., 2008
Forced change in employment

Creating economic changes

View of self as ineffective
Encountering barriers

Internal: injury-based

External: resource and access-based
Ability to access to information
Availability of adequate social supports
Systems and policies which provide for needed resources
Economic resources to support living and participation

Living with changes
What has happened to me?

Recognizing the changes to competencies and capacities
“It’s me, but it’s not me”

Struggling with insight into deficits and changes
“It’s not the same person”

Dealing with responses from others
Experiencing withdrawal and isolation

From others

By others
Understanding that happiness is a property of groups of people.

A person with a brain injury and those around them may be unhappy

The “cascade” effect occurs in illness and disability as a source of unhappiness for the person and others.

Relatives’ criticism influences adjustment and outcome after brain injury:
Association between distress, coping and recovery

Weddell R. Arch Phys Med Rehab. Vol 91, June 2010, 897-904
Can we better understand this process through the people involved?
Can we use their stories to understand the impact of brain injury on their lives?
How did they deal with the losses created by their injuries?
People

Stories
Ray

Ray, was a promising middleweight boxer who started his career at age 14. By his early 20’s he had experienced multiple concussions and left boxing. At age 44 he was diagnosed with Parkinson Syndrome and Dementia Pugilistica
“...I had my first concussion at 16 in Buffalo, New York when I took a right hook to the back of my head...”
“one week later I was scheduled to fight in Syracuse. I knew something was wrong- I got my “bell rung” in the first round...”
“...I vomited in my water bucket but stayed in the fight. I didn’t even remember that I lost the fight in the post-fight interview...”
“...the fog lingered. I started having problems in school, trouble concentrating, headaches, sleeping excessively and resenting authority...”
“...I battled through and asked a trainer about the headaches and fatigue. He told me to “gut it out”.”
“...In 1971 I failed the required EEG for the New York State Boxing Commission license. I fought in places were no license was required. I returned in 1973 for a re-test and my EEG was grossly abnormal....”
“....In 1974 I took a break from boxing-the symptoms didn’t go away. I threw out my boxing memorabilia. I went into a mental health facility and was diagnosed with severe depression...”
“... I took to the road for a while and avoided everybody. I took refuge in the National Parks....”
“...14 years later I couldn’t continue working at my job due to tremors. I was diagnosed with Parkinson Syndrome and Dementia Pugilistica...”
“...The only thing I could do was prevent another athlete from going down my path...”
Now, at 61, Ray is the founder of The Second Impact, a not-for-profit brain injury prevention program. He provides talks to athletes-amateurs, university and professional teams about concussion recognition and prevention. He has turned his losses from brain injury into a way to help others.
Craig

Craig was injured at age 10. He remembers waking up in traction and feeling his forehead which felt like a shallow bowl. He had been in a coma for 3 weeks. Craig went back to school, attended several colleges, eventually graduating with a Master’s degree in Rehabilitation Counseling, but failed at every job. He now operates Second Chance to Live and shares his self awareness with others.
“I grew up in perfectionism and constantly was saying ‘sorry’ for things. I felt responsible for everything”
“I had to struggle with living with an invisible disability. Once the external wounds heal-brain injury is never considered to be an issue”
“I felt I was different, couldn’t put my finger on it... absorbing it internally, it was something wrong with me”
“I had difficulties in my practicum and internship. The Dean at my graduate school told me that he couldn’t tell me if I was graduating until an hour before I graduated.”
“I got a job and got fired. I got another job at the Department of Voc Rehab and they made me a client. Then I got another job and got fired. In 1998 I was found to be unemployable and granted disability”
“I started training in different martial arts to develop my brain on both sides and improve fine and gross motor skills. Through martial arts I learned the journey is more important than the destination”
“I could replace perfectionism with the pursuit of excellence. I had to get to a place where I could move beyond the pain of denial and not accepting my reality, before I could grieve my reality.”
“I fumbled my way to learning to use what I had to work for me.”
“People are told to identify themselves within the box where they are placed. People need hope and freedom for exclusion. I needed to have self-empathy to allow myself to leave the box”
Craig, now 58, is determined to “give back” to others struggling with brain injury. He has developed a website, A Second Chance to Live, and writes self-help books which he makes available through his site and others. He asks rehabilitation professionals to change their attitudes towards survivors and consider them as peers and partners.
Dan

A 45-year old corporate vice president who was injured in a plane crash and left with severe physical impairments and faced divorce and separation from his daughter.
“Do you know what it’s like to hear your doctor tell your wife that it’s never going to be the same, that I probably wouldn’t walk or talk again?”
“I knew that if I worked harder than anybody else I would get back what I lost”
“My wife told me that she was divorcing me and taking my daughter. How can she do that to me?”
“I’ve been back at work for a few weeks now and it’s just not the same. People aren’t the same around me, it’s like they don’t trust me. I can do my job but it doesn’t feel right”
“It’s been over a year since I’ve been back at work and but my job isn’t the same for me. I started the legal process to regain custody of my daughter. I started looking into getting a Masters’ degree in Social Work. I want to help other people with brain injuries”
“Last night was my first date since my divorce. It was hard to tell someone that I had a brain injury. Once I got that over with, the evening went a lot better”
Dan completed his degree in social work and regained custody of his daughter. He works with people with disabilities who are returning to university. We laugh about his “first date”
Jerry

I met Jerry when he was a 20-year old university student, injured at 19. Following a short period of acute rehabilitation he experienced a deep depression which didn’t clear.
“I tried to go back to school, but I couldn’t concentrate”
“getting C’s and B’s just wasn’t me. I was used to getting straight A’s”
“It was hard to hang out with my friends. Somehow we weren’t the same anymore. It was easier to be alone”
“I thought about killing myself a lot. I went up to the roof and thought about jumping, or taking an overdose. It was impossible to tell my family about how I felt”
“I stole Sherri’s car and I thought today was the day. I looked into the back seat and I saw the baby’s car seat. I had to bring the car back”
Jerry ended his life by driving his car into a bridge abutment about 3 years after he left our program. He was finishing university. I see his mother often. She has become very involved in advocacy work.
Vladimir

A 55-year old electrical engineer with a wife and 3 older children. He was experiencing cognitive problems at work and having angry outbursts.
“I don’t know what’s wrong with me. It’s like my brain isn’t working. Things I used to know how to do, I can’t anymore”
“I don’t like asking anyone for help, my wife or you or anybody. People used to come to me for help and now I’m coming to you”
“I got so mad I was going to kill my wife and my daughters and then kill myself. I knew that I needed to call before I did something”
“I don’t like to need help, it’s not my nature. I put myself through school and earned money to take care of my family. This accident took that away in a second”
“Things started to get better when my therapist gave me some tools to remember things. I’m still a smart man, but I needed to prove that to myself”
Vladimir’s recovery didn’t take him back to where he was pre-injury and he struggled with depression and asking for help. Eventually, he allowed his wife to help in his business.
A recent university graduate, Jamil, 23, was opening a business to support his mother and younger siblings. A motor vehicle accident left him with cognitive and psychological problems.
“you know that I’ve been dealt a bad hand with this brain injury. I was just getting my business going when this happened”
“As the eldest, my mother was my responsibility after my father died. And now, I can’t do what I need to do. I’m supposed to be taking care of her, but look how she has to take care of me”
“I need rehab to get myself back on track, to learn what I need to do to run my business. I don’t know if you guys understand that”
“Sometimes I get so angry at myself, you and everybody around me. Other times, I’m sort of thankful that I came here”
“I started working with my cousin. He’s going to help me out in the business. It's not what I planned, but at least I can take care of my responsibilities”
Jamil returned to his business and was able to take care of his family. For a few years, he came back every few months and would lead a group discussion about life after rehab. After a while, he said he was too busy at work. But, I heard he was married and became a father.
What are the tasks to be done?
How does life get put back on track?
Or, find another track?
How does a person re-establish self-value?
How do they learn to like who they are now?
Or, grieve for what was lost?
How do they learn to change what they can and accept what they can’t?
Can they start their life again?
How can the person respond to depression?
How can they rebuild relationships?
What part of this work is solely theirs to accomplish?
And, what part belongs to other people?
Facilitating the recovery phase

What can work?
Disordered Mind, Wounded Soul: The Emerging Role of Psychotherapy in Rehabilitation After Brain Injury
Denial of changes of functioning, not a deficit of self-awareness

Prigatano, G., 1999
Rehabilitation must focus on the disordered mind and the wounded soul

Prigatano G. 1991
“Focus on discovering the meaning of their lives in the face of, not despite, the brain injury”
“Teaching the person to behave in their own self-interest”

Prigatano G., 1991
Examined Lives: Outcomes After Holistic Rehabilitation

Ben-Yishay, Daniels-Zide, 2000
Viewing their life as meaningful
Wellness includes: environmental mastery, personal growth, positive relationships, purpose in life and self-acceptance
Does attainment of optimal outcomes require that the individual achieve an examined self?
Clinical professionals need a better understanding of how people make sense of themselves, especially after extreme circumstances.

Medved, M, Brockmeir, J., 2008
Helping survivors of a traumatic event see the positive and assist the survivor in de-victimizing themselves—creating opportunities for positive thinking and growth

Taylor, Wood, Lichtman, 1983
What people search for in a rehabilitation professional?
One who listens to them
One who respected their goals
One who showed an understanding of their situation

Jumisko E, Lexell J, Soderberg S., 2005
Rational Frame Theory
Developing a new self-concept

Redefining Self
Conceptualized Self
Self as an ongoing process of verbal knowledge
Self as context
Experiencing loss in the context of perceived loss of competencies
Experiencing distress over the loss of competency: Anger, depression, anxiety, grief
Treatment occurs in the context of reconciling the post-injury self with the pre-injury person
Post-injury self

Not able to use skills

Feeling incompetent

Loss of creativity

Loss of Work life
The person arrives at a painful self-awareness between their pre-and post-injury capabilities.
Through experiencing the self in context the person can move away from the negative view of self.

Creating a safe place to experience the changes from injury and identify a new self.
“...Identity is a growing and changeable thing”.. “…The tragedy which occurred can be inserted into one’s narrative and shape their identity…”

McAdams, 1993, 1994
Acceptance and Commitment Therapy (ACT)

The person becomes “stuck” due to fear.

The healthy alternative is to “act”
Accept your reactions

Choose a valued direction

Take action

Myles S., 2004
Person experiences intense anxiety post-injury
Conceptualized as a defense of pre-injury self-concept

Myles S., 2004
Guiding the person to accept their post-injury functioning
Supports building a new self-concept
Supports pursuit of key life values
Teaching the person to become non-judgmental and accepting of self
Mindfulness supports the increasing awareness of self

Supporting the separation of distressing symptoms from the person without encouraging denial
Using therapy to address the inconsistency between pre-injury self concepts and post-injury functioning
Perception of control enhances resiliency

Can we teach people to exert control over what has happened to them?
Assist the person in attempting an alternative to "failure"

Reframing negative reactions to real situations:

You can do it!
“This injury does not define my life, I define it. Life can be powerfully lived in this condition”
How can we help people in this process of finding themselves and, in a way, reinventing themselves?
How can rehabilitation professionals help with the process of recovery of self?
“The longest way round is the shortest way home”

James Joyce
Hope and fear are both phantoms that arise from thinking of self. When we don’t see the self as self, what do we have to fear?

Lao-tzu
My personal thanks to the many people and their families who shared their experiences with me and helped me to understand the process of loss and recovery of self.
Thanks!

Questions?
This presentation can be found at traumaticbraininjury.net under “Resources” and “Community Presentations”.

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