Life After Severe Brain Injury: the Restoration of Self and Social Role Return

Rolf B. Gainer, PhD
Rehabilitation Institutes of America, Novato, CA
Neurological Rehabilitation Institute at Brookhaven Hospital, Tulsa, OK
Community NeuroRehab, Des Moines, IA

Disclosure

Rolf B. Gainer, PhD has business relationships with Rehabilitation Institutes of America, Brookhaven Hospital, Community NeuroRehab of Iowa and their related companies. The NRIO and CNR Outcome Studies referenced in this presentation are supported by those organizations.

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Objectives:

To understand the process of recovery of self in relation to social role return
To consider the changes in social relationships after brain injury

To identify the barriers faced by the person in addressing loss
To understand what can facilitate change

How does the person perceive what happened?
We see ourselves as we were yesterday, not as we are today.

We may not be happy with who we have become or what has happened to us, especially after an event which has changed our life.
Brain injury is destabilizing

How does the person reconcile with who they now are as compared to who they were prior to the event?
“The most devastating loss of all becomes a loss of the meeting of the minds”

Paula Freed, 2002
“Our only truths are narrative truths, the stories we tell each other and ourselves- the stories we continually recategorize and refine”

Oliver Sacks, The River of Consciousness, 2017

Psychological health is dependent on our ability to change and revise memory.

What happens when the person’s ability to access memory is impaired?
Brain injury can change a person’s self-awareness and ability to express emotion making it difficult to describe who they are now.

The person faces loss of self and loss of social role.
“Social membership” requires acceptance and recognition by others

Joseph Carens, 2013

What happens as life goes on?
Three categories of loss

Nochi, 1998

Loss of clear self knowledge
Loss of self by comparison

Loss of self in the eyes of others
Depression and loss disrupt the person’s sense of social stability

Source: Frank, et al. (2005)

Grief for the loss of the healthy self

Frank, E et al (2005)
which came first?

Loss of sense of self

or

Relationships
What do people see when they see themselves?

Is the view of self consistent with what other people see?
How do we recognize what we see vs. what others see?

are they linked?
Which must be addressed first?

Which aspects are the work of the person to accomplish?
What is related to the responses of people and groups external to the person?

The person:
Validation of self occurs through the “narrative self”

“Each of us constructs and lives a ‘narrative’, this narrative is us”

Oliver Sacks
Our lives become a story about ourselves

What happens to our story after disability from brain injury?

Does the narrative end or shift to what the person remembers?
Is this the point where the story we built becomes one of living in the here and now?

How does the person begin to construct a new self?
Or, do they deny that anything has changed?

“Each day, we wake slightly altered, and the person we were yesterday is dead.”

John Updike, BrainPickings.org
Do people “get stuck” in who they were or do they live in the present?

How can we better understand the impact of the event and its aftermath on the person?
Memory and attention impairments effect the quality of relationships

“Events are not traumatic until we experience them as traumatic”

George Bonanno, 2016
Loss, Trauma and Emotion Lab, Columbia University
“Events are not predictive until there is a negative response”

George Bonanno, 2016

Disability and loss of role function produces a decline in self-worth as perceived by the person and others

Source: Condelucci, A. (2008)
Is this the point where we encounter isolation and withdrawal?

How does social isolation effect health after disability?
Disengagement from naturally occurring social units

“connectedness”

The perception of relationships
The recognition of emotion and affect
The ability to exercise decision making over behavior

Relationships are critical to our self worth and social role return.

Brain injury disability accelerates the aspects of social network failure which lead to isolation and withdrawal.
Let’s return to what George Bonanno addressed in defining response. How does resilience impact on personal response and social participation?

**Resilience**: an illusive factor in aging with a disability
Resilience and long-term functional outcomes

Resilience may protect mood and prevent depression

Resilience may increase social participation
There is no measure for resilience, it is the person’s response to adversity, obstacles and threat which determines how the person will fare with each event

Emmy Werner, 1989

Resilience is a constant recalculation of factors relating to multiple stressors over time

Emmy Werner, 1989
Resilience may change from pre-injury baseline as a person ages with a brain injury disability


“Events are not predictive until there is a negative response”

George Bonanno, 2016
Brian Little refers to “our multiple selves” made up of our “fixed” or biogenic traits and our “free” or sociogenic traits.

How does injury exert change on the person’s biogenic traits and their sociogenic traits?

Brian Little, 2014
Brain injury impacts both the “fixed” and the “free” aspects.

Understanding the process of recovery of self may help us to understand resilience.
Do people have different “susceptibility” factors?

And, can those factors change over time?

Can we enhance a person’s likelihood of a positive response to an adverse event?
Core Traits Associated with Resilience

Even Tempered, Stable Emotionally
Positive Outlook, Optimism
Self-regulatory skills
Social Perception, “Liked” by others
Insightful modification of behavior
Good problem-solving skills
Effective communication

Many of these traits are affected by brain injury
Let’s shift from the person to their relationships with others.

social role:
the characteristic or expected social function of a person or thing, especially in a particular situation or environment;
a collection of behaviors, attitudes, responsibilities, and expectations related to a particular niche a person fills.
Establishing the scope of the problem:

Can we identify what causes social role difficulties following brain injury?

Let’s focus on aspects of mutuality and participation
Depression and loss disrupt the person’s sense of social stability

Source: Frank, et al. (2005)

Does it mimic psychiatric illness?
Does it mask psychiatric illness?

Is the person with a brain injury and a dual diagnosis more likely to experience social role return problems?
How do we measure self-worth?

job, profession, skills
relationships, family, friends
life activities
home/residence ownership
positive feedback
participation with others
Disability and loss of role function produces a decline in self-worth as perceived by the person and others.


self-worth = SOCIAL CAPITAL
Self-worth: a factor of “social capital”? 
- The value of a person is created by the individual and their society
- The roles a person occupies and their effectiveness in those roles creates value

What is the effect of social capital? 
What happens for the person?
As social capital decreases, stress increases

Kawachi Ichiro

Resilience requires social capital
Social capital relates to other capital...

People with disabilities experience disproportionately high rates of poverty

Does disability related poverty increase social exclusion and social network failure?

Can we look at long-term outcomes for the person through the different lens involving the social network?
Social Network participation: the impact of disability

Our social network: degrees of separation occur over the lifespan

- Primary Relationships
- Children grow up
- Friendships
- Parents age/death
- Social participation declines
- Community participation fades
- Ability to work changes

Can we look through the lens used by Christakis and Fowler and see the reduction in social network activity?

Social network Theory:
Christakis and Fowler

Can we better understand the social impact of brain injury on long-term outcomes?

Brain injury disability accelerates the aspects of social network failure which lead to isolation and withdrawal.

A brain injury will effect others in the person’s social network. It will create changes in the quality and quantity of relationships.
The person’s ability to adhere to rules of social membership can cause exclusion

Exclusion = Isolation
Are negative emotions contagious?

Does exclusion begin to occur?

What about looking outside of rehab?

Does the research on emotions and social media offer an understanding?
Sadness causes withdrawal social deactivation


How do other people react when a person is sad and depressed?

I HATE LIFE!

Can they sustain the relationship?
Rage and anger are transmitted faster through social networks, triggering a chain reaction.


Do family members “disconnect” when the person has behavioral problems?

What happens when they disconnect?
How does the person view themselves after injury?

The loss of a sense of self is a common experience.


Self-estrangement, negative self-evaluation, emotional distress and denial of changes in functioning

View of self as “not the same person”

Loss of sense of competency and effectiveness at work, home and in social relationships

Does the loss of sense of self drive withdrawal?
what’s the difference between isolation and withdrawal?

How does injury severity and residual deficits impact on long-term social integration?
What causes social withdrawal?

What are the dynamics of social withdrawal?
What are the effects of isolation?

Is loneliness a component of social network failure?
“It was hard to hang out with my friends. Somehow we weren’t the same anymore. It was easier to be alone”

Jerry M.

What is the role of psychological resilience in adjustment?
“The better I got, the more aware I became of my deficits which made me even more depressed about my prospects of the future”

Laurie Rippon

What can we learn from individuals who make a successful return?
“...I started to feel OK about myself when I started volunteering and getting involved in peer counseling...”

Melissa Felteau

“When life was turned upside down I began to focus on what really mattered to me. That set me on the way to a new life—one I could be proud of”

Laurie Rippon
“I learned to feel good about each small step of progress, which gave me the confidence to look to the next step... until I felt more whole”

Laurie Rippon

What can we learn from people who don’t succeed in social role return?
degrees of separation

brain injury impacts on social role
The NRIO Study
1997-2017

the people over the course of the study:

751 tracked from 1995-2017
Average age: 32.1
Age Range: 21.1 to 78.7
100% Severe TBI
90.3% MVA
### the NRIO cohort

- **age at injury**: 27.8
- **GCS <9**: 83.1%
- **male/female**: 61.3% / 38.7%
- **period from injury to post-acute**: 27.8 months
- **months in prior rehabilitation**: 94.55 days
- **% MVA related**: 90.3%

### the NRIO Study:

- Social Role Return
- Independence/Support Level
- Vocational/Avocational Activities
- Mental Health and Substance Abuse Issues
- Durability of Outcome
let’s look at the issues with adults with a TBI and a psychiatric disorder prior to post-acute rehabilitation

NRIO Outcome Study, Adult Cohort
1997-2017

pre-admission characteristics
33% legal problems due to social behavior & judgment

36% post-injury substance abuse
45% problems with spouse or significant other

88% Problems relating to/maintaining friends
2.5 years post injury prior to admission


1 to 5 years after the injury

nrio outcome study, adult cohort
1997-2017

36.40% Returned to pre-injury social role without modifications

55.45% Required modified pre-injury social role
8.15% Required extensive support by paid or family caregivers

55.45% Required minimal to moderate mental health care to support social role return
24.1% experienced significant psychological problems requiring intervention

Is this the group in which we will observe social role return problems?
Let’s look at a study with five years of operation and a similar population

CNR Study
2011-2016
the CNR cohort

age at injury: 17.33
50% of discharges injured prior to age 10
male/female : 83.33%/16.67%
period from injury to post-acute: 11.0 – 15.5 years
Pre-injury psychological problems: 77%
Pre-injury substance abuse: 33%
Pre-injury legal problems: 44%

pre-admission characteristics
44% legal problems due to social behavior & judgment

55% post-injury substance abuse
45% problems with spouse or significant other

88% Problems relating to/maintaining friends
Returning to pre-injury social role in 2016

16.7%

Returned to pre-injury social role without modifications
0%
Returned to pre-injury role with modifications/supports

83.3%
Interfering psychiatric problems and/or substance abuse problems affecting social role
0%
Returned to pre-injury role with Minimal modifications/supports

Is this the group in which we will observe social role return problems?

83.3%
The search for answers: why are there differences in outcome attainment?

NRIO and CNR: Essential Differences

Age at time of injury
Length of time from initial injury to treatment
Number of “failed” treatment events
NRIO and CNR: Essential Differences

Pre-injury mental health and substance abuse issues
Post-injury mental health and substance abuse issues
Availability of post-injury and post-treatment supports

The search for answers: why are there differences in outcome attainment?
A person’s history is key to understanding how they will react to their brain injury


How can change be facilitated?

What are the key elements of change?
Self knowledge comes in bits and pieces...

The trick is how we assemble them?

Or, maybe re-assemble them.
“...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

“I learned to feel good about each small step of progress, which gave me the confidence to look to the next step... until I felt more whole”

Laurie Rippon
“We create ourselves as a work of art”


“Being the same person over time is not about holding on to every aspect of our current selves; instead it is about changing purposefully”

M. Foucault, 1983
Brain injury disability may prevent the person from access to their abilities to change...

How can we facilitate positive change?

Thank you!

Questions?
This presentation may be accessed at traumaticbraininjury.net under “Resources”, then “Community Presentations”
Resources and References

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