Long-term Social Role Difficulties for the Person with Brain Injury and a Psychiatric Diagnosis

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Disclosure

• Rolf B. Gainer, PhD has business relationships with Brookhaven Hospital, the Neurologic Rehabilitation Institute of Ontario, Community NeuroRehab and Rehabilitation Institutes of America

• The studies conducted by Brookhaven Hospital, Community Neuro Rehab and the Neurologic Rehabilitation Institute are self-supporting and receive no public or private grant monies.
objectives:
To review the key studies involving people living with brain injury and co-occurring mental health disorders
To consider the dynamics involved in social role in the years post-injury
To understand the implications of social role return in long-term outcomes from brain injury
To identify resources needed to prevent aspects of social role return problems which effect quality of life and health
Advisement: Some slides may contain images which could be disturbing
social role, n., (səʊʃəl rōl): a network of mutuality based on participation.
Let’s look at the process which this woman went through 20 years ago. Can we better understand the social role issues through her story?

“...I received 64 floral arrangements from my friends... nobody came to visit me after my discharge...”
“...right after the accident my parents, younger sister and brother were my support network...”
“...my parents replaced my functions in the home. They took care of everything...”
“...I tried to go back to work...”
“...my job could not accommodate post-injury needs...”
“...my social relationships fell off as people recognized my deficits...”
“...they didn’t know how to make it comfortable...”
“...we weren’t operating in the same social circles anymore...”
“...I felt vulnerable due to my brain injury...”
Can we identify the mileposts in her journey?
How does injury severity and residual deficits impact on long-term social integration?
What is the role of psychological resilience in adjustment?
What causes social withdrawal?
What are the dynamics of social withdrawal?
What is the relationship of cognitive flexibility to post-injury adjustment?
Is social participation an aspect of the person’s measure of post-injury adaptation?
What are the effects of isolation?
Is loneliness a component of social network failure?
Could the outcome have been different?
Examining mental health supports: what is needed?
Can we effectively intervene to support social role return?
How do we measure self-worth?
job, profession, skills
relationships, family, friends
life activities
home/residence ownership
positive feedback
participation with others
self-worth
=
social capital
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?
Disability and loss of role function produces a decline in self-worth as perceived by the person and 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)
life changes.
injury-based changes changes
every aspect

each relationship
Can we look at long-term outcomes for the person through a different lens?
The chronic nature of brain injury related disability effects the person throughout their lifetime.

Let’s examine the sociogram of a 22-year-old with a severe brain injury.
Meet Rick at 22
What has happened over the course of time to his family? social network? family? friends?
The challenge of today’s survivor: “Sicker and Quicker”

Mark Ashley’s study
17 days of acute medical care in 2012 vs. 57 days in 1990 for high moderate to severe injuries

Source: Ashley, M. Santa Clara Valley Brain Injury Conference, 2012
Home quicker, but at what cost?
Will shortened rehabilitation impact on long-term social role return?
How will the person, family and social network deal with the stressors?
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?

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

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

- Study involved 454 Canadians, average 13 years post TBI
- 66% required ADL assistance
- 75% not working
- 90% dissatisfied with social interaction
- 47% not talking with others by telephone
- 27% never socialize at home
- 20% never visit others

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
where does the person with both brain injury and mental health problems go?
Do specific aspects of brain injury relate to social role return?
Social role return and frontal lobe function

Is there a connection?
Theory of Mind applied to social network integration

How does the person’s ability to perceive others impact on their social role?
Is our social role functioning determined by frontal lobe function?

- Emotional recognition
- Infer mental states of others
- Social Cognition
- Cognitive Flexibility
- Executive Functioning

The “I” function and social role return

• Capacity to maintain a sense of self
• Relating abilities
• Capacity to initiate behavior/activity
• Ability to respond/reciprocate
• Recognition of self among others
• Maintaining the “Social Rhythm”
Can we understand apathy as a factor in social role disruption?

The loss of the capacity to initiate affects relationships.
Apathy and Social Role Return

- Individual may not fully sense their altered role behaviors and performance
- Ability to participate in relationships is reduced
- Significant response by others to changes in functional status “...not the same person...”
- Loss of responsiveness to requirements of role
- Lack of initiation of behaviors integral to role
Apathy is associated with a reduced emotional and physical response

83% of TBI cases with apathy had comorbid depression

Differentiation of “social apathy” an altered sense of self and social awareness related anterior frontal lesions

Apathy may exist as subtypes defined by frontal-subcortical loops (Apathy Syndromes)

Apathy: Who Cares?

Is social role function determined by injury location?

- Apathy found in adult TBI at a prevalence range of 46.4% to 71.1%, average of 61.4%
- Loss of role and hopelessness found in most individuals with apathy
- Apathy may not be concern to the individual due to a loss of self-observation
- Caregivers rate apathy as the third most difficult neurobehavioral problem
Are negative emotions contagious?
What about looking outside of rehab?

Does the research on emotions and social media offer an understanding?
“The Fast and the Furious”

Does the strength of the emotional and behavioral content speed communication?
Rage and anger are transmitted faster through social networks, triggering a chain reaction.

Similar to past studies involving the families of individuals with brain injuries, behavioral dyscontrol is the hardest for family members.
Does the presence of a neurobehavioral syndrome effect long-term outcomes?

self-regulation issues trigger problems
Do family members “disconnect” when the person has behavioral problems?

What happens when they disconnect?
Sadness causes withdrawal and social deactivation

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

Can they sustain the relationship?
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?
Establishing the scope of the problem:
Can we identify what causes social role difficulties following brain injury?
Defining the duration of the problem

Does the problem change over the course of time?
“The tragedy of the human brain is that it is aware of what it has lost and where it is headed—both at the same time”

Walter Mosley, “When the Thrill is Gone”, 2011
What are the risk issues?
What are the mental health issues?
Depression
Anxiety
Mood state problems
Risk for Suicide
Irritability, anger and aggression
High risk behaviors
Other Mental Health Problems
Does it mimic psychiatric illness?
Does it mask psychiatric illness?
and, the relationship to physical health and wellness
Brain Injury
What are the barriers?
Financial, structural, individual, and attitudinal barriers directly impede individuals’ abilities to access rehabilitation services even though these services could greatly improve their recovery from TBI.

Defining the barriers

- Poor/fair general health 53%
- No health insurance 56%
- Limitations in ADL 54%
- Unemployed 56%
- Cognitive Problems 55%
- No adequate social support 64%
- Non-White males 49%

Source: Leopold, A. (2013)
Medicaid recipients reporting “unmet needs”

Source: Leopold, A. (2013)
Does limited rehab increase problems in social role return?
What do the research studies tell us about brain injury and future mental health problems?
Can those studies help define the issues related to social role return?
Geurtsen’s study on sustaining outcomes
Can rehabilitation outcomes be sustained?

- Life functioning and community integration gains can be sustained after rehabilitation
- Areas studied included:
  - Living accommodations
  - Employment
  - Hours of care needed

Source: Geurtsen, G.et al. (2010)
J. Ponsford’s study
Functional Outcomes 10 years after injury

- High levels of anxiety and depression = poorer outcome attainment
- Level of ability to participate = poorer outcomes
- Social isolation related to functional deficits
- Psychiatric diagnosis and cognitive deficits are best regarded as components rather than outcomes

Source: Ponsford, J. et al. (2008)
The Monash University Study
Monash University Study: Likelihood of post-injury psychiatric disorders

• Psychiatric disorders occurring in 60% of the post-injury population in a 5.5 year period

• Greater likelihood of psychiatric disorder found in relationship to pre-injury substance abuse, major depressive and anxiety disorders

Kaponen’s 30-year study
30-year study of mental health issues and brain injury

• Temporary disruption of brain function leading to the development of psychiatric symptoms

• Increased, long-standing vulnerability and even permanent psychiatric disorder

Source: Kaponen, S., et al. (2002)
30-year study of mental health issues and brain injury

• 61.7 had an Axis 1 (DSM-IV) diagnosis in their life time
• 48.8% had an Axis 1 diagnosis following their injury
• 40.0% had a current, post-injury Axis 1 diagnosis
• Depression (MDD) was the most common diagnosis

Source: Kaponen, S., et al. (2002)
J. Silver’s HMO Study
HMO Study of mental health issues

• Severe TBI related to higher rates of depression (MDD), dysthymia, OCD, phobias, panic disorders, substance abuse/dependence, bipolar disorders as compared to the non-TBI group

• “Poorer physical or emotional health and higher likelihood of receiving welfare for the TBI cohort”

• Negative symptoms of psychiatric disorders enforce social isolation and social network failure

R. van Reekum’s studies
R. Van Reekum’s Study

• Depression found in 44.3% - 50.0% of cases over a 7.5 year period
• Anxiety Disorders found in 9.1% - 16.6%
• Substance abuse in 27.7%
• Personality Disorders in 12.7%
• Denial of symptoms could prevent an understanding of cognitive, emotional and behavioral difficulties

Meichenbaum’s Study of Resilience
70-80% of people exposed to trauma recover successfully.

20-30% continue to experience lingering clinical disorders and adjustment problems such as PTSD, anxiety, depressive and substance abuse disorders that can result in suicidal acts, aggressive behavior and divorce.

Fann, et al
Fann et al: Self perception

• Individuals with both depression and anxiety perceived themselves as more ill and demonstrated reduced function as compared to cohort with anxiety without depression

What do the long-term studies tell us?
Is the person with a brain injury and a dual diagnosis more likely to experience social role return problems?
Dawson and Chipman’s study of living in the community with a brain injury
Reviewed the quality of life, assistance needs and level of socialization experienced by individuals 13+ years post moderate-severe brain injury living in both rural and urban environments

Dawson and Chipman: quality of life, support needs and socialization

- 66% need ADL assistance
- 75% unemployed
- 90% dissatisfied with social life
- 47% not using telephone
- 27% not socializing at home

Health and Aging with a brain injury
Life expectancy after TBI

• Twice as likely to die as age, gender and race matched peers

• Estimated life reduction of 7 years

Health disparities
Increase in health issues post-TBI

- 15 times more likely to die from seizures
- 5 times more likely to have mental health or behavioral problems
- 3 times more likely to die from aspiration pneumonia, sepsis, nervous system disorders, digestive problems and assaults
- 2 times more likely to die from suicide, circulatory conditions and unintentional injuries

What are the economic aspects of brain injury disability which affect social role return?
People with disabilities experience disproportionately high rates of poverty.

Does disability related poverty increase social exclusion and social network failure?
What happens when rehab is over?
What happens as life goes on?
what about social role return?
is it a determinant of potential mental health problems?
What is related to the person’s brain injury disability?
What is related to the responses of people and groups external to the person?
what’s “normal”?
normal:

• according with, constituting or not deviating from a norm, role or principle occurring naturally
what’s normal after a brain injury?
who determines what’s “normal”? 
When is “normal” reached?
how can we expand the domains we measure to be more relevant to the person and their life?
“create a new baseline and not go back to where they were”

Alya Reeve, MD,

“Every 21 seconds or why I scream at the refrigerator” a film by Laura Napier and Doug Claybourne, New Mexico Brain Injury Advisory Council, 2006
outcome:

- something that follows as a result or sequence

- Synonyms: aftereffect; aftermath; backwash; conclusion; consequence; corollary; development; fate; effect; outgrowth; product; result; sequel; sequence; upshot
A. Condelucci’s view of living with a brain injury disability

What are the life outcomes?

Source: Condelucci, A. (2008)
Work?

76% are unemployed
Home ownership?

6.1% own their home
Transportation?

The majority are not driving
Friendships and personal relationships

Many people experience the loss of relationships
Let’s look at outcome data from two community-based programs
the NRIO study
the people over the course of the study:

641 tracked from 1995-2014

Average age: 32.0

Age Range: 2.11 to 78.7

83.3% Severe TBI

90.5% MVA

the NRIO Study:

Social Role Return
Independence/Support Level
Vocational/Avocational Activities
Mental Health and Substance Abuse Issues
Durability of Outcome

the NRIO cohort

- age at injury: 32.0
- GCS <9: 83.3%
- male/female: 68.3% / 31.7%
- period from injury to post-acute: 25.00 months
- % MVA related: 90.5%

the NRIO cohort in 2014

- age at injury: 36.2 vs. 32.0 study average
- GCS <9: 85.5% vs. 83.3%
- male/female: 68.3% / 31.7%
- period from injury to post-acute: 35.5 vs. 25.00 months
- % MVA related: 90.5%

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
1997-2013

3.4 years post injury prior to admission
33% legal problems due to social behavior & judgment
36\% \text{ post-injury substance abuse}
45% problems with spouse or significant other
88% Problems relating to/maintaining friends
1 to 5 years after the injury

**nrrio** outcome study, adult cohort

1997-2014

perception of post-injury changes

- cognition
- behavior
- emotions
- physical abilities
- relationships
- level of participation
- level of independence

37.3% return to their primary social role without modifications.

43.1% experience a change requiring support and role modification.

19.6% experienced significant psychological problems requiring intervention

19.6%

Is this the group in which we will observe social role return problems?
Is there a commonality of problems for the individuals in this group?
What are the mental health issues?
How does substance abuse impact on social role return?
What factors prevent returning to their pre-injury social role?
What happens to individuals who don’t return to their pre-injury social role?
What supports are needed to sustain outcomes over the course of time?
What can we learn from individuals who make a successful return?
What can we expect as changes in outcomes over the course of time?
Let’s look at a study with three years of operation and a similar population with different outcome results
CNR Study
the CNR Study:

- Social Role Return
- Independence/Support Level
- Vocational/Avocational Activities
- Mental Health and Substance Abuse Issues
- Durability of Outcome
the people over the course of the study

28 tracked from 2010-2014
Average age: 39.21
Age Range: 34.10-60.00
Age at injury: 31.90
100% Severe TBI
33% MVA
22% Aneurysm
22% Assault
22% Anoxic Injury/Toxic Encephalopathy
the CNR cohort

age: 39.21

male/female : 72%/27%

period from injury to post-acute: 1.0 – 20.0 years

Average from injury to post-acute admission 8.0 years
Post-injury, pre-admission problems

Pre-injury psychological problems: 77%
Pre-injury substance abuse: 70%
Pre-injury legal problems: 57%
CNR Outcomes

Employed: 10%
Not working/unable to work: 90%
Independent Living with 0 to 4/hrs day of support: 20%
Independent Living with 6-10/hrs day of support: 20%
Living with family 0-4/hrs day of support: 20%
Living in care situation: 40%
Substance Abuse Issues

Post-discharge substance abuse: 40%
Maintaining abstinence: 60%
Minimal substance use: 10%
Moderate substance use: 30%
Returning to pre-injury social role

Returned to pre-injury social role: 20%

Returned to pre-injury role with modifications/supports: 40%

Interfering psychiatric and substance abuse problems affecting social role: 40%
Individuals who don’t return to their pre-injury social role

Weekly counseling: 0%
Occasional counseling: 30%
Receiving daily support 2-6/ hrs day: 10%
Attending self-help/support group: 0%
Not receiving psychological/psychiatric services: 30%
Requiring 24 hr placement: 40%
40% experienced significant psychological problems requiring intervention

40%

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

The length of time from injury to rehabilitation creates persistent problems.
Why?

The development of chronic mental health and substance abuse problems which effect participation and engagement
Why?
The loss of personal, family and social network supports over time resulting from psychiatric and substance abuse problems related to brain injury
Let’s take another look at Cathy...
“...I started going back to school...”
“...I started to feel OK about myself when I started volunteering and getting involved in peer counseling...”
“...it took me six years to integrate...”
“...I started to develop self-compassion...”
“...the third hurdle was getting my master’s degree...”
now, 20-years since her injury, an accomplished researcher in Mindfulness, a published journal author, conference speaker and teacher.
The search for answers
What can we learn from people who don’t succeed in social role return?
What can we learn from durability?

What are the factors associated with sustained long term outcomes?
Where do we need to look to make meaningful changes?
Sustaining caregivers

What resources are needed by caregivers to maintain their healthy roles?
Can housing be healthcare?

How can we integrate sustained supports in the home?
Eliminating health disparities
Mental health services across the lifespan
Supports for social integration
Programs for the person...
unique, person centered programs
Targeting loneliness and isolation
Can we establish strategies and interventions for individuals with a dual diagnosis?
Where will funding come from?
Eliminating barriers as they occur... throughout the lifespan
“you can observe a lot by watching”

Yogi Berra
"That's all Folks!"
Thank you!
Questions?

This presentation may be downloaded at www.traumaticbraininjury.net
nrio.com

It can be found under “Resources”
The presentation cannot be copied, used or distributed without the consent of the author.
Resources


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Resources


Resources


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The Psychometrics of Social Role Return for the Person with Brain Injury

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