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

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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 the Neurologic Rehabilitation Institute of Ontario and Community NeuroRehab 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
social role, n., (səʊʃl 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...”
How do we measure self-worth?
job, profession, skills
relationships, family, friends
life activities
home/residence ownership
positive feedback
participation with others
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
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)
What are the mental health and risk issues?
Anxiety
Mood state problems
Risk for Suicide
Substance abuse
Irritability, anger and aggression
High risk behaviors
Can research studies help define the issues related to social role return?
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)
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

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)
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 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

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.

Meichenbaum: Reslience

- 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.

Life expectancy after TBI

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

- Estimated life reduction of 7 years

The chronic nature of brain injury related disability effects the person throughout their lifetime.

Dawson & Chipman’s study 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’s quality of life, support needs and socialization

- 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

Does isolation and loneliness create social network failure?
Social Network Theory: Christakis and Fowler

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

Sadness causes withdrawal and social deactivation

Brain injury disability accelerates the aspects of social network failure which lead to isolation and withdrawal.
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?
Does apathy separate the person from relationships because of loss of role function and ability to reciprocate?
Or, do others separate from the person because of their perception of the changes in the person’s ability to relate to them?
a chicken or egg problem?
Is the person with a brain injury and a dual diagnosis more likely to experience social role return problems?
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 (ongoing)
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%

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
1 to 5 years after the injury

Outcomes and Stability
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?
CNR Study

2010-2013 (ongoing)
the CNR Study:

Social Role Return

Independence/Support Level

Vocational/Avocational Activities

Mental Health and Substance Abuse Issues

Durability of Outcome
the CNR cohort

age at injury: 37.72
male/female: 72%/27%
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%
33.3% return to their primary social role without modifications

22.0% experience a change requiring support and role modification.

44.0% experienced significant psychological problems requiring intervention

44.0%
Is this the group in which we will observe social role return problems?
What is the major difference between the NRIO and CNR cohorts?

25 months vs. 11-15.5 years post injury
Is the time between injury and treatment a factor to consider in the development of social role return problems?
Let’s take another look at Cathy, 10 years later...
“...I started going back to school...”
“...I started to feel OK about myself when I started volunteering and getting involved in peer counseling...”
“...I started to develop self-compassion...”
now, 22-years since her injury, an accomplished researcher in Mindfulness, a published journal author, conference speaker and teacher.
Is social participation an aspect of the person’s measure of post-injury adaptation?
Can we facilitate the process of change?
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 authors
Resources


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Resources


Resources


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Resources


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