The Double Whammy: Living with a Brain Injury and a Psychiatric Disorder

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Disclosure Statement

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

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addressing the realities of a co-occurring diagnosis
today’s goals
today’s goals

To develop an understanding of the problems faced by an individual with a brain injury and psychiatric problems in their long term return
today’s goals

To understand the community-based resources which are needed by the person with a brain injury and a psychiatric disorder
today’s goals

To consider how an amalgam of strategies and interventions are needed to sustain participation and involvement
today’s goals

To understand the role of brain injury in the mental health population
what do we know about TBI?

1.5+ million new cases a year
what about severity?

75-80% of the brain injuries in the U.S. civilian population are “Mild”
“Mild” Brain Injuries can have significant long-term consequences.

There is nothing “mild” about Mild Brain Injuries.
Moderate and Severe Brain Injuries cause significant disability with physiological, cognitive, psychological and behavioral changes.
Brain Injury can create a lifetime of disability
we could fill six cities the size of Detroit with people living with the effects of brain injury in America today.
what groups contain individuals with brain injury?

- Mental Health 25%
- Substance Abuse 40%
- Prison population 65-70%
- Homeless 80%
what about returning veterans?

• Estimated 150,000 – 300,000 have a TBI (2000-2010)
• Nearly 10% of all service members
• 30% of all Walter Reed AMC admissions
• 18.5% of all service members have PTSD = 472,000 diagnosed with PTSD
• 25% are experiencing mental health problems
• 17.5- 22.00/100,000 have attempted suicide
psychosis depression anxiety disorders mania affective disorders posttraumatic stress disorder aggression irrational
every page of the DSM
where do we find the roots of mental health issues?
let’s consider brain injury and mental health issues in the context of social relationships and social network participation
what about social role return?

is it a determinant of potential mental health problems?
by addressing the realities of a co-occurring diagnosis
life changes.
injury-based changes

changes

changes

changes
every aspect

each relationship
In the early phases of recovery, some behaviors can resemble a psychiatric illness.
pre-injury mental health problems can be exacerbated by a brain injury
what came first?
psychopathology ?

or

neuropathology ?
Does it mask psychiatric illness?
Does it mimic psychiatric illness?
what is it?
the NRIO study
the people over the course of the study:

614 tracked from 1995-2012

Average age: 31.6

Age Range: 2.11 to 78.7

100% Severe TBI

89.05% 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: 31.6
- GCS <9: 83.5%
- male/female: 67.4% / 32.6%
- period from injury to post-acute: 21.00 months
- % MVA related: 89.5%
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
1997-2012
2.5 years post injury prior to admission
36%

Pre- and post- injury substances abuse problems
45% problems with significant other
45%

trouble maintaining relationships with friends
family members perception of problems post-injury
Functional Physical Limitations
Chronic Medical Care Needs
Reliance Upon Others for Basic Care
Transportation
Depression
Cognitive Problems
Behavior and Anger Management Problems
what our participants saw as key changes in their lives post-injury
1 to 5 years after the injury

nrío outcome study, adult cohort
1997-2010
perception of post-injury changes

- cognition
- behavior
- emotions
- physical abilities
- relationships
- level of participation
- level of independence
why are the participants perceptions of post-injury changes different from those of family members?

relationships
participation
independence
perception = reality
mental health and TBI
Unemployment + depression + anxiety
substance abuse
risk for suicide
long term outcomes

- employment problems
- decreased sense of well-being
- suicidality
- risk of seizures

substance abuse
TBI: Pervasive Effects
cognitive changes underlie behavioral responses
cognitive deficits

interaction

post-injury behavioral disturbances
behavioral responses contribute to risks
How do we measure self-worth?
job, profession, skills
relationships, family, friends
life activities
home/residence ownership
positive feedback
participation with others
What parts of me will change after a brain injury?
aspects of brain injury increase psychological problems over time
RISK FACTORS
related to the onset of mental health problems

- age
- pre-injury psychiatric problems
- pre-injury substance abuse
- poor work/social adjustment history
- problems in support networks
degrees of separation
the risk for behavioral health problems increases in the years following an injury
brain injury impacts on social role
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
what happens after rehab?

1yr 5yrs 10yrs

after rehab?
10 years after the injury and rehab

nrrio outcome study 1997-2012
37.3% return to their primary social role without modifications
43.1% experience a change requiring support and role modification
0% regression
19.6% experienced significant psychological problems requiring intervention
are these the people with a “Dual Diagnosis”? 
coping styles 2
avoidance
worry
blame
drugs
humor
relaxation
problem-solving
disability shift
brain injury creates a risk for a mental health trajectory

- age at onset of disability
- male vs. female
- low/reduced social supports
- financial hardships
an increase to the risk for crisis...

requiring emergency mental health services
crisis events increased isolation and withdrawal
will neurobehavioral problems be misunderstood?...
...during a crisis event
the response to mental health emergencies

where do I go in a crisis?
does social isolation contribute to the development of neuropsychiatric symptoms?
what’s the difference between isolation and withdrawal?
Is loneliness contagious?
Meet Rick at 22

mother

best friend

art school
Brain Injury and Mental Health

- 93.7% of BI providers reported working with dual diagnosis clients
- 48% estimated more than 26% of clients had a mental health diagnosis
- 20% estimated more than 50% of clients had a mental health diagnosis
- 23.1% of mental health providers indicated that clients with BI were not eligible for services

Source: Toronto Acquired Brain Injury Network newsletter, Spring 2011
does the person with a brain injury fit the mental health network?

or

does the person with mental health issues fit the brain injury network?
where does the person with both brain injury and mental health problems go?
or, will they be on the edge of two networks?
What network is the person with a dual diagnosis supposed to participate in?
isolation occurs when the person can't participate...
they are moved to the edge of the network
“fitting in” increases opportunity/participation
social networks affect our lives
we operate in clusters
but, how much relates to the person?
each network has relationship effects

induction

homophily

confounding

contagion
the circles of relationship clusters overlap
is contagion caused by emotional or behavioral changes?
and, what part comes from social network membership?
do networks move people within the network?
what about the rippling effect?
...people who don’t fit are found at the edges
does the social network theory help us understand what happens to relationships?
social networks change size and complicate over time.
Social network membership requires certain behaviors.
where are the answers?
let’s start small
what can we learn from children with TBI about the issues faced in adulthood?
brain injury in childhood: the lifespan issues
Long Term Implications

- High survival rate for moderate to severe problems 5-8 years post-injury.
- Risk of future mental health issues.
- Social isolation due to functional and behavioral issues.
- Need for extended family supports.
brain injury in childhood will effect the person throughout their lifetime, increasing the risk of mental health problems
two years later

1997-2009, nrio outcome validation study, pediatric and youth cohort
20% returned to grade level
required program changes
40% required psychological supports
60% returned with modified social role
today’s child with TBI is tomorrow’s adult
can we see the roots of problems in adulthood when we look at children with a severe brain injury?
Meet Bobby at 9

father mother

siblings

school
children grow
parents
age
age
participation declines
does rehab ever end?
how does TBI impact social role?
“fit problems”

Cognitive
Behavioral
Emotional
Physical
family
friends
work
community

4 components of a social network
as changes to the person’s social network occur and functional problems increase with age, what happens?
neuropsychiatric and neurological features
brain injury: a STARTLING reality
positive and negative roles
helpless
unemployed
patient
what happens to the person who isn’t able to give?
Meet Walter at 55
the distancing effect
loss of interpersonal connectivity
social role adjustment

it’s complicated.
the TBI Bias: one year later an elevated risk
are these the people with a “Dual Diagnosis”?
neuropsychiatric features of brain injury
unemployment

lastling psychological and social functioning problems

aggressive behaviors

depression

family strain

diminished relationships

dependence
cognitive problems

executive dysfunction

impulse control

memory problems

social withdrawal

emotional response to injury
brain injury and mental health problems reduce the number of available connections...
people move towards the fringe where there are fewer connections to make
living on the fringe of two networks:

Brain Injury or Mental Health
and an increased separation from the center of pre-injury networks of family, friends, work and community.....
how do TBI and Mental Health problems impact on social networks?
76% unemployed
what about severe brain injury?
what factors prevent participation?
The Canadian Study
by Dawson and Chipman
61% depression 7+ yrs post-injury
apathy
66% need ADL assist
90% dissatisfied with social life
75\% unemployed
47% not using telephone
27% not socializing at home
35% unmet needs
43% concerned with the realities of a long-term disability
isolation
isolation & social withdrawal stifle interaction
does apathy + isolation = depression?
Let’s look at a study involving people with TBI living in nursing homes. Staff report that 50% could be living elsewhere.
but, where?
where you live can make you depressed

neighborhoods with poor social cohesion increase likelihood of stressful events

Ahern and Gales, Collective Efficacy and Major Depression in Urban Neighborhoods. Am J Epidemiol 2011 April 28
does TBI disability create a forced choice… 

by moving people away from social networks?
does marginalization set the person up for mental health problems?
or does the person’s mental health problems set them up for marginalization?
another chicken or egg problem?
Where's the data?
few resources that support independence
what about mental health and aging with a severe brain injury?

what are the barriers?
brain injury accelerates psych conditions
the TBI Bias: one year later an elevated risk
aging

with a brain injury
by 80 the average person has 3 disabling conditions...
Remember Bobby?
support & care needs increase
functional abilities

required supports
what happens when a caregiver dies?

where does the person go?
change in routines

problems associated with loss of a loved one

search for other caregivers

economic upheaval
social network and aging
why don’t we ever talk about the real costs?
disability + aging = $\ldots$
$15 million projected over the person’s lifetime
TBI: The Ultimate Stressor
barriers to reintegration increase
lack of resources
restrictive settings
divergent treatment
what about the people?
how can we reach out to the person better?
better tools, better skills
building relationships between service providers
making supports work through integration
helping the person return to their lifestyle
prevention and wellness strategies
supporting caregivers to sustain the person
responding to costs of lifetime disability with real $’s
creating the right resources and expertise
plan and measure
what’s important?
- Early identification and intervention
- Development of mental health resources with TBI expertise
- Understanding risk factors
- Creating a capacity to respond to crisis
- Providing ongoing supports in the home and community
- Providing caregiver support
can we fix
what is broken?
are we committed?
thank you.
nri at brookhaven hospital

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This presentation can be found at: traumaticbraininjury.net under “Resources”

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