Moving through the lifespan with a brain injury: What really happens to people?

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Disclaimer

Rolf B. Gainer, PhD has business relationships with Brookhaven Hospital, the Neurologic Rehabilitation Institute of Ontario (NRIO) and Community Neuro Rehab (CNR) and Rehabilitation Institutes of America.

Nancy Weber, MA,CBIS is employed by Brookhaven Hospital

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Learning Objectives

• To consider outcomes as dynamic and evolving in the years post-injury
• To conceptualize brain injury as a chronic disease which affects the person as they age
• To regard social role return as a key aspect of the person’s post-injury life
• To examine factors which effect the person as they age
In an ideal world, where would we start?
“create a new baseline and not go back to where they were”

Alya Reeve, MD,
Brain Injury: a cumulative disability
Brain Injury is a lifetime disability
What are the long term issues associated with brain injury?
before we get to the long-term issues, let’s regard Brain Injury as a chronic disease
What defines a chronic disease?

World Health Organization, 2002

- Permanent
- Leaves a residual disability
- Caused by a non-reversible pathological alteration
- Requires special training of the person
- May be expected to require a long period of supervision, observation and care
Brain injury: a disease process

TBI is not solely an event
...but a process which continues to exert changes over the course of a person’s life....
Brain injury: an illness?

this view isolates the impact of the injury on the entire person
it creates expectations of a person’s return to their pre-injury status without problems
when we look at the effects of a brain injury on a person, we need to regard the chronic nature of the disabling conditions
let’s consider what parts of brain injury we see
Icebergs and brain injury: Why are they alike?
10% of an iceberg is visible
We see the 10% of the iceberg that occurs in the first 18-24 months following the injury.
Most peoples’ lives post-rehabilitation are not followed to observe how their brain injury has changed their lives......

that’s the 90% we don’t easily see
Brain injury creates changes
for the person
and, for the people around them
TBI: not a static process
Impact on organ systems
Disease causative and accelerative
Affects the person over the course of time
creates a change of direction
Focus on the “residual effects”

What are the barriers?
Physical
Psychological
Behavioral
Post-injury medical problems:

- Hearing, vision problems
- Diabetes
- Skin integrity problems
- Swallowing problems
- Sleep apnea
- Parkinson’s Disease
- Circulatory problems
Let’s expand our view to include the impact of brain injury on others
The impact of disruptions in the living situation
And, the effects on others
Including Caregivers
Let’s consider what’s important to caregivers...
Intimate relationships
Family
Children
Friends
Co-workers
The impact on personal finances
The true cost of brain injury
$15-17 million over the course of a person’s life
The effects of caring for a disabled family member
Is there caregiver support?
what resources are available for the caregivers such as...
Information about brain injury
Social support from family, friends, community
I need a vacation so badly, I've resorted to plotting my own kidnapping.
Long-term planning
What happens as caregivers age?
How to deal with the increase in medical conditions
Increased sense of burden
Addressing disruptions caused by new or exacerbated problems
and, the impact on medical and social support needs long after the injury.
What happens when a caregiver dies?
Other family members or caregivers?
Finding an alternative living situation
How can we assist people in maintaining independence?
Can vs. Can’t

Transportation
Can vs. Can’t

Healthcare Services
Can vs. Can’t

Social supports
Sustained community integration: what’s involved?
Let’s consider:

what’s important to people?
Personal Life & Relationships
Social Role Return
Meaningful life activities
Community participation
Eliminating health disparities

Healthy Life
NEXT EXIT

Brain Injury
Exit Here
what are the barriers to sustained outcomes?
Mental health problems
The likelihood of psychological problems over the course of time.
Substance Abuse Issues
High risk individuals
Responding to mental health crisis
and, the onset of health problems
What do the long-term studies tell us?
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)
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

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
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 A 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

• Source: Silver, J et al (2001)
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

Source: Whelan-Goodinson, Johnston, Ponsford, Grant (2009)
Dawson and Chipman’s study of social adjustment

- Based on life satisfaction of individuals >15 years post-injury
- Measures included: personal assistance required; employment status; socialization; contact by telephone
- Social isolation and lack of opportunities identified as a key factor in adjustment difficulties

Source: Dawson and Chipman (1994)
What happens when rehab is over?
What happens as life goes on?
Can we sustain the gains made in rehab over the course of time?

What does it take?
What’s changing tomorrow’s outcomes?
Increased survivability
Earlier medical intervention
but, shorter medical rehab
Individuals with greater disabling conditions being sent home “sicker and quicker”
17 days of acute medical care in 2012 vs. 57 days in 1990 for high moderate to severe injuries
What services will individuals who are discharged at 17 days post-injury need?
How does that **impact** on outcome?

Are community-based services available? **Adequate?**
Is there caregiver support?
Cumulative effects of stress on caregivers
Limited resources for caregivers
Priority issues for caregivers
What happens as caregivers age?
What happens when a caregiver dies?
The long view of living with a brain injury disability
A view of the complex effects on the person

The Canadian Study, Dawson and Chipman, 1994
Level of life satisfaction
Personal care requirements
Return to sustained employment
Restricted social contacts
Sustained community integration: what’s involved
Housing?
Transportation?
Healthcare services?
Social supports
Support for social role return
Key elements to consider:

Isolation and loneliness
Withdrawal
High level of dependence on others
Limited socialization opportunities
Loss of life focusing activities
Onset/presence of barriers
Let’s examine outcomes from several ongoing studies.

What can we observe?
NRI/Brookhaven Study
1996-2012

Inpatient neurobehavioral program
Return to home and community with moderate supports <6 hours/day

6% required minimal to moderate supports in 2012

94% required extended to full supports > 6 hours/day
Social Role Return

14% returned to their primary social role with independence or minimal modifications

19% returned in a dependent care status

33% required 24 hour/day supervision
Interfering behavior and psychological problems

23% required no ongoing psychological or behavioral supports

67% required weekly or greater psychological or behavioral supports
Return to Work

6% returned to competitive employment, vocational training or school

22% returned to supported employment and volunteering

44% were unable to sustain any work or volunteering activity
there needs to be a bridge back into the community
NRIO Study
1997 to 2012
Community-based rehabilitation
From 1997 to 2011 the age at injury increased 37.6 years in 2011 vs. 30.7 in 2001 in the Adult cohort
Home support needs following discharge

25% requiring a level of paid support in the home
Community participation and access

51% requiring full to partial support for community participation
Adults returning to their pre-injury social role without supports

40.9% in 2012 vs. 29% in 2001
Focus on Social Role Return

• 14% unable to maintain pre-injury role in primary relationships

• 14% report change in role due to functional status

• 40.9% report remaining in role but experiencing minor problems
Interfering factors to social role return

• 31.8% reporting post-rehab substance abuse problems

• 40.9% reporting post-rehab behavioral health problems
Pre- and post-injury psychological/psychiatric problems

- 33% report pre-injury psychological/psychiatric problems
- 56% report post-injury psychological psychiatric problems
Psychiatric Problems Pre- and Post-Injury

- 22% report pre-injury depression
- 38.9% report post-injury depression
- 11.1% report pre-injury mood disorders
- 16.7% report post-injury mood disorders
- 11.1% report pre-injury anxiety disorders
- 44.4% report post-injury anxiety disorders
Pre- and post-injury substance use/abuse

• 38.9% experience pre-injury substance use/abuse problems
• 50% experience post-injury substance use/abuse problems
Return to Work

• 50% unable to return to work due to injury related problems
• 14% returned to their pre-injury job
• 7% required job modification/changes/supports to return to work
• 7% “volunteering” or retraining
Durability of outcome

• 0% regression in social role return level
• 0% increase in paid attendant care services
• General trend towards increased independence over time
post-rehab supports are needed
Community Neuro Rehab Study
2010-2012
Community-based neurobehavioral rehabilitation
Age at injury: 36.33
Return to pre-injury social role

25% return to their pre-injury social role with no to minimal supports
Focus on social role return

- 25% are unable to maintain their pre-injury role without moderate to maximum supports
- 25% are experiencing a substantially changed social role due to functional problems
Home support needs

75% requiring more than 2 hours/day of paid support
Community participation and access

75% require paid support to access the community
Pre- and post-injury substance use/abuse problems

• 75% had pre-injury substance abuse problems
• 50% had post-injury substance abuse problems
Pre- and post-injury psychological/psychiatric problems

• 37.5% had pre-injury psychiatric problems
• 100% had post-injury psychiatric problems
Return to work
• 62% were not able to return to their pre-injury job
• 25% returned to work with job supports and modifications
• 25% participated in further vocational training
• 25% engaged in volunteer activities
What can we learn from outcome studies that can improve long term outcomes?
Impact of physical, cognitive, behavioral and functional symptoms on relationships
Marital stability, divorce and separation rates range from 15% to 78%.

Goodwin, Kreutzer, Arango-Lasprilla, Lehan, 2011
Johnson et al., 2010
not significantly different from the general population studies

but, what can we do to enhance supports to sustain relationships?
Neuropsychological and psychological effects

Medical and physical issues

Relationship changes
Impact on caregivers due to family stress, revised roles, isolation, increased dependence

Boschen, Gargaro, Gan, Gerber, Brandys, 2007
Gosling and Oddy, 1999
Oddy, 2001
Oddy, Coughlan, Tyerman, Jenkins, 1985
Psychological changes effecting the person, their mood and behavior

Kaponen et al, 2002
Whelan-Goodinson, Johnston, Ponsford, Grant, 2009
Fann, et al., 2004
Injury severity and the latent onset of mental health problems

Fann, et al., 2004
Gillett L, 2007
Van Reekum, et al, 2000
Silver, et al., 2001
Pre-injury problems and post-injury psychiatric and substance abuse

Dikmen, et al., 2004
Jorge, et al, 1993
Federoff, et al., 1992
Gomes-Henerandez et al., 1997
What are the key questions to consider?
What issues are barriers to community participation?
What are the types and frequency of support needs?
How can we identify the barriers to attaining greater independence?
How can we help to identify realistic goals for the person?
How can we determine resources needed by family caregivers over the course of time?
What about aging?
Aging with a brain injury

Brain injury is a cumulative disability
By the age of 80, the average person has at least three disabling conditions doesn’t that occur much earlier for people with brain injuries
Let’s look at a cohort of 8 individuals in a community-based supported living environment.
The demographics:

- 7 males, 1 female, >20 years post-injury
- 55-69 years of age
- 88% Motor Vehicle Accidents
- 100% were employed pre-injury
Changes to their family support systems since their injury

- 12% have no contact with family
- 50% have experienced the death of one or both parents
- 75% have reduced contact with family members
What health problems are they facing now that they are > 20 years post injury?
Decreased mobility

• 25% using walkers
• 25% using wheelchairs
Development of medical problems post-injury

Diabetes in 25%
Skin integrity problems 25%
Circulatory problems 25%
Seizure disorder 12%
Swallowing problems 25%
Sleep apnea 25%
Parkinson’s Disease 25%
Hearing, vision problems 75%
Psychological/Psychiatric Problems

- 50% report ongoing depressed mood
- 50% report problems with anxiety
- 100% report problems with fatigue
Let’s also look at people who are living successfully with their brain injury disability.
Some people do well

What can we learn from their successes?
What characteristics can be associated with positive long term outcomes?
The person

- Strong, resilient personality
- Positive, forward looking
- Manages day-to-day life needs
- Understands their need for support
- Minimal psychological issues
- Maintains focus on meaningful life activities
- Maintains social role
Their family

• Oriented towards mutual help
• Identifies and accesses supports/resources
• Supports maximum independence
• Maintaining their own health/wellness
• Maintains other life interests
• Adequate financial resources
• Supports social roles within and outside of family
Their social network

• Friends and social life available outside of the home and family
• Frequent social contacts through multiple means: activities, telephone, electronic
• Combination of old and new friends
• Positive social experiences
The available resources

• Finances to support lifestyle
• Adequate, accessible housing
• Access to transportation
• Access to routine and specialized healthcare
• Access to community activities
• Addressing the process of aging with a disability
Resources and References


• Napier, L., Claybourn, D. (2006). *Every 21 seconds or why I scream at the refrigerator* [DVD format]. (Available from New Mexico Brain Injury Advisory Council, 505-476-7328 or elizabeth.peterson@state.nm.us).


Resources and References


Questions?

Note: this presentation can be downloaded at [www.traumaticbraininjury.net](http://www.traumaticbraininjury.net) under “Resources”
The impact of disruptions in the living situation
Finding an alternative living situation
Addressing disruptions caused by new or exacerbated problems
What about support for participation?

How can we assist people in returning to independence?