Aging and Brain Injury: Expectations and Realities

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Disclosure

• Rolf B. Gainer, PhD has business relationships with Brookhaven Hospital, the Neurologic Rehabilitation Institute of Ontario, Community NeuroRehab of Iowa 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 understand brain injury as a chronic disease which affects the person throughout their lifetime
To consider co-morbid conditions which affect the process of aging with a brain injury
To understand the accelerated process of aging related to people living with a brain injury
Brain Injury is a lifetime disability.
Brain Injury: a cumulative disability
Age and Disability: Shared Issues, Different Timing
Age and Disability: Shared Issues
TBI Disability Based
Age Based
Mobility problems
Functional losses
Memory and cognitive problems
Sensory impairments
Health problems
Loss of independence
Reduced income
Depression
Loss of peers/ social withdrawal
Aging

Neuroplasticity decreases with age

Atrophy increases with age

The process of aging can have a greater effect on a person with a brain injury
Same problems

Different timeframe for onset
Disability and Future Healthcare Needs
Increased vulnerability to specific diseases cause premature entry into “frail elderly” group.

Decreased access to health maintenance and wellness programs.

Early onset of chronic health problems associated with disability.
Likelihood of experiencing new health conditions related to functional loss

Likelihood of experiencing longer and more complicated treatment for health problems

Greater needs for DME, poorer adjustment to assistive devices

Source: DeJong, 1997
how can we learn to measure at multiple points in the lifespan?
to accurately address changes over time
Health disparities effect quality of life and, the relationship to physical health and wellness
Creates a change in direction
how can we understand the \textbf{sequence of life changes} following brain injury?
we need to start by looking at changes within the brain at the time of injury: are there biomarkers other than outward function?
Pro-inflammatory and anti-inflammatory processes

Endocrine and immune system changes

Do these processes affect how the will person age?
How do behavioral influences like diet, sleep and exercise impact these functions?
Can we intervene to stall the neurodegenerative process?

Will that exert change on how a person ages with a brain injury?
We hear about outcomes...
Do outcomes change over time?

What really changes?

The person?

The measurement?
maybe changes continue to occur just like in everyone’s life
We also hear about “normal”
Who determines what’s “normal”? 
When is “normal” reached?
Is there a typical brain injury?

How does that relate to the aging process?
Let’s look at some research to identify issues that we see beyond the original injury.
Does this research help us to understand the process of living 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
Health disparities

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

Health disparities and increased disease likelihood affects longevity creating a more vulnerable and fragile population of people aging with a brain injury.
Age and sex-specific life expectancy were lower than the U.S. general population

Age, male gender, injury severity and degree of disability in walking and self-feeding relate to increased mortality

Older individuals (≥40) with less severe injuries but greater disability than younger individuals showed greater decline over the first five years.
A higher risk of cognitive and functional decline was seen with older individuals.
History of traumatic brain injury associated with increased risk for dementia and Parkinsonism, cognitive impairments and decline, seizure, hormonal disorders…

Ishibe N, et al, Long Term Consequences of BI, a report to the Institute of Medicine, 2009
...and **long term emotional and social problems and unemployment**

Ishibe N, et al, Long Term Consequences of BI, a Report to the Institute of Medicine, 2009
Loss of independence creates increased needs
Independence decreases for individuals 45-64 and ≥65

Need for part and full time supervision increases for individuals 45-64 and ≥65

Long-term outcomes of brain injury disability
Disengagement from naturally occurring social units
The aging process in the increasing years since injury

Declines in physical and cognitive functioning

Declines in societal participation

Source: Sendroy-Terrill, et al, 2010
Cognitive, physical and societal functioning are influenced by the severity of the injury.

Source: Sendroy-Terrill, et al, 2010
Fatigue identified as a key factor in functioning and participation
Fewer environmental barriers reported as people age with a brain injury

Adaptation or reduced societal participation?

Source: Sendroy-Terwill, et al, 2010
Increased age at injury predicts decline in functional independence

Creating increased care needs

Source: Sendroy-Terrill, et al, 2010
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)
How do psychological changes impact on a person’s return to living their life?
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)
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

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.

The onset of health issues and functional impairments reduce the person’s ability to participate in activities which support independence.
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
Resilience may change from pre-injury baseline as a person ages with a brain injury disability

Let’s look at a cohort of 10 individuals in a community-based supported living environment to consider the problems they are experiencing.
The demographics

9 males, 1 female, ≥ 20 years post-injury

100% Severe Brain 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 33%
- Skin integrity problems 25%
- Circulatory problems 25%
- Seizure disorder 12%
- Swallowing problems 50%
- 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
Mortality 20%

Male 62- Massive MI

Female 69- Bowel obstruction, sepsis
100% requiring medical, nursing and attendant care to manage health, living and mobility.
Brain Injury: Not a Single Disability

Severity related factors
Increased survivability with greater functional deficits
Increased comorbidity
Caregiver stress

Mobility and access issues

Reduced income, onset of disability related poverty
Brain injury: a disease process

TBI is not solely an event
when we look at the effects of a brain injury on a person, we need to regard the chronic nature of the disabling conditions
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: 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
...but brain injury is a process which continues to exert changes over the course of a person’s life...
Icebergs and brain injury: Why are they alike?
We see the 10% of the iceberg that occurs in the first 18-24 months following the injury.
10% of an iceberg is visible, 90% is below the surface.
The chronic nature of brain injury related disability effects the person throughout their lifetime.

and, for the people around them
Depression and loss disrupt the person’s sense of social stability.

Source: Frank, et al. (2005)
Mental health and substance abuse issues change outcome potential
1 to 5 years after the injury

nrio outcome study,
adult cohort
1997-2014

Source: Gainer, R., et al. (1997-Ongoing)
Person’s perception of post-injury changes

- cognition
- behavior
- emotions
- physical disabilities
- relationships
- level of participation
- level of independence
family members
perception of problems
post-injury
Functional Physical Limitations
Chronic Medical Care Needs
Reliance on Others for Basic Care
Behavior and Anger Management Problems
Cognitive Problems
Depression
Transportation
the person and their loved ones have a different understanding of changes
why are there variances in the perception of changes and problems?
do the differences represent what is important to the person vs. their family’s view?
37.3% return to their primary social role without modifications

Source: Gainer, R., et al. (1997-Ongoing)
43.1% experience a change requiring support and role modification.

Source: Gainer, R., et al. (1997-Ongoing)
19.6% experienced significant psychological problems requiring intervention

Source: Gainer, R., et al. (1997-Ongoing)
What can we expect of these cohorts as they age?
Age and Brain Injury: Outcomes of Injury
55% of individuals injured >65 were severely disabled or died vs. 86% of moderately injured <65 had good recoveries or required ADL assistance (Pentland, 1986)
Age Severity and Outcome

Two to five year post injury: >50 had longer hospital stays and were more dependent in ADL’s and less likely to be working than <25 (Davis and Acton, 1988)
Mechanism of injury falls vs. MVA’s account for more mass lesions in ≥65 population (Goldstein, et al, 1994)

Dementia ≤70 associated with earlier severe brain injury (Heyman, 1984)
Observation: Age at the time of injury is a significant factor in outcome
Now, let’s review a study involving individuals at the 15 year point post-moderate to severe brain injury and consider issues of participation and perception of quality of life.
Dawson and Chipman’s study

Quality of Life for individuals with severe and high moderate brain injuries ≥15 years post-injury, living in urban and rural settings
47% not using telephone
66% need ADL assistance
75% unemployed
61% depression 7+ yrs post-injury
57%
clinically significant depression
50% anxiety & depression in severe TBI
Why?
interference of symptoms
ability to self-manage
cognitive ability
physical functions
How does that appear over the course of time?
Meet Walter at 55
Walter at 55

Walter at 65

son

ex-wife

wife

father

daughter
care and support needs increase over time
fewer supports
to provide them
According to Caregiver Action Network:

(http://caregiveraction.org/statistics/#Caregiving Population):
More than 65 million people, 29% of the U.S. population, provide care for a chronically ill, disabled or aged family member or friend during any given year and spend an average of 20 hours per week providing care for their loved one.

(Source: Caregiving in the United States; National Alliance for Caregiving in collaboration with AARP; November 2009)
The value of the services family caregivers provide for "free," when caring for older adults, is estimated to be $375 billion a year.

(Source: Evercare Survey of the Economic Downturn and Its Impact on Family Caregiving; National Alliance for Caregiving and Evercare. March 2009)
That is almost \textbf{twice} as much as is actually spent on homecare and nursing home services combined ($158 billion)

(Source: Evercare Survey of the Economic Downturn and Its Impact on Family Caregiving; National Alliance for Caregiving and Evercare. March 2009)
47% of working caregivers indicate an increase in caregiving expenses has caused them to use up ALL or MOST of their savings.

(Source: Evercare Survey of the Economic Downturn and Its Impact on Family Caregiving; National Alliance for Caregiving and Evercare. March 2009)
Family caregivers experiencing extreme stress have been shown to age prematurely. This level of stress can take as much as 10 years off a family caregiver's life.

Loss of independence is costly

Housing Choice

Returning to live with parents or family in a dependent status

Difficulty in accessing services outside of the home

Source: NRIO Outcome Study, 1993-2014
Loss of independence is costly

Difficulty in obtaining TBI support services
Finding resources with brain injury expertise
Economic changes

Source: NRIO Outcome Study, 1993-2014
Disability and loss of role function produces a decline in self-worth as perceived by the person and others.

Source: Condelucci, A. (2008)
isolation and social withdrawal stifle interaction
aging hides TBI
Health risks increase with age
Individuals living with a brain injury disability and have limited financial resources are more likely to experience health problems.
Hospitalizations

Admission issues change over time
Long term healthcare resource utilization

Severity of injury, physical/cognitive and psychosocial disability all predict service utilization.

Individuals 6-48 months post injury used services related to restoration of function.

Individuals 72-204 months post injury used services in response to life changes such as loss of relationship or caregiver.

Hodgkinson, 2000
TBI and Re-hospitalization

3 Years Post Injury

50% of admissions for orthopedic and reconstructive surgery

15% for seizures

Psychiatric hospitalizations doubled in years 1-2, leveling off in year 3

Cifu, 1999
TBI and Re-hospitalization

5 Years Post Injury

Orthopedic and reconstructive surgery admissions declined

Incidence rate for seizures and psychiatric admissions increased

Marwitz, 2001
Costs of Care Increases With Age

TBI costs associated with acute care increased at twice the rate for general medical care (Kreutzer, 2001)

Increased motor disability associated with total charges (Vangel, 2005)
Coping and adaptive strategies learned in rehabilitation fail as individuals become middle aged and senior citizens for mild to moderate injuries

(Klein, 1996)
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.

Source: Leopold, A. 2013
few resources that support independence
Does limited access to adequate financial resources accelerate problems?
The high cost of a bump on the head

Highest rate among 15-19 year old Males:
550/100,000 vs 115/100,000
The high cost of a bump on the head

Increased survivability for younger individuals
The high cost of a bump on the head

Lifetime costs projected $4.5 to 5 million
(Bilmes, L, 2007)

and $8 to 17 million
(Livneh and Antonak, 1997)
$17 million?
Will outcomes change in the future?
The challenge of today’s survivor

“Sicker and Quicker”

Source: Ashley, M. (2012)
17 days of acute medical care in 2012 vs. 57 days in 1990 for high moderate to severe injuries

Source: Ashley, M. (2012)
The Future
Problems and Planning

Today’s injuries
tomorrow’s aging
with a disability
More People Survive, Less Resources to Share

“Sicker and Quicker” reduced stays in acute medical care
More survivors with greater disability levels and comorbidities
Increased lifetime costs associated with severity and longevity

Source: NRIO Outcome Study 1997-2014; NRI Outcome Study 1993-2014
Today’s Injuries
Tomorrow’s Disabilities

*Increase in medical technology* preserves life for individuals with severe injuries.

*Increase in survivorship* increases the extent and level of disabilities experienced by people.

*Improvements in healthcare* extends the lifespan of people living with disability.
Are the resources available to support people as they age with a brain injury?

What resources are needed?
Aging and Brain Injury: Addressing Long Term Needs

Increase availability of accessible housing, transportation and community supports

Eliminate healthcare disparities
Aging and Brain Injury: Addressing Long Term Needs

Provide economic supports and income supplements to avoid disability based poverty.

Provide lifetime supports for caregivers and family members.
Aging and Brain Injury: Addressing Long Term Needs

Address critical transition events which trigger crises and problems

Make available professional healthcare resources who can address the issues of aging with a brain injury
How do you address the problems associated with aging with a brain injury?
Thank you!
This presentation can be downloaded at traumaticbraininjury.net. Look under “Resources” on the header, then “Community Presentations”
Resources


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Resources


Resources

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