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 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
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disabling
conditions
Age and Disability: Shared Issues
TBI Disability Based

Mobility problems
Functional losses
Memory and cognitive problems
Sensory impairments
Health problems
Loss of independence
Reduced income
Depression
Loss of peers/ social withdrawal
Age Based

- Mobility problems
- Functional loss
- Hearing and vision loss
- Memory and cognitive problems
- Health problems
- Loss of independence
- Reduced income
- Depression
- Loss of peers/
  social withdrawal
Same problems

Different timeframe for onset
• 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
Healthy Life
NEXT EXIT
Brain Injury
and, the relationship to physical health and wellness
creates a change of direction
how can we understand the sequence of life changes following brain injury?
We hear about outcomes......
do outcomes change over time?

what really changes? the person? or, the measurement?
maybe changes continue to occur....

..just like in everyone’s life
We also hear about “normal”....
What’s “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 regarding health and mental health issues 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
- 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

Long-term outcomes of brain injury disability
Disengagement from naturally occurring social units


Christakis C, Fowler J., 2008
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

Source: Sendroy-Terrill, et al, 2010
Fewer environmental barriers reported as people age with a brain injury

Adaptation or reduced societal participation?

Source: Sendroy-Terrill, 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

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

perception of post-injury changes

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

Source: Gainer, R., et al. (1997-Ongoing)
family members perception of problems post-injury
Functional Physical Limitations
Chronic Medical Care Needs
Reliance on Others for Basic Care
Transportation
Depression
Cognitive Problems
Behavior and Anger Management Problems
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
Facts: Age, Severity and Outcome

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 assist
75% unemployed
61% depression 7+ yrs post-injury
57% clinically significant depression
50% anxiety & depression in severe TBI
Why?
cognitive ability
interference of symptoms
ability to self-manage
How does that appear over the course of time?
Meet Walter at 55
Walter at 55

Walter at 65

son
ex-wife
wife
dad
father
daughter
community

aging
caretaker
Care and support needs increase over time
What about “Caregivers”?

- Age/gender of caregivers
- Health problems of caregivers
- Physical capacity of caregivers
- Financial Issues
- Limited resources
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 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.

isolation & social withdrawal stifle interaction
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

• 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
The high costs of a lifetime of disability

- Highest rate among 15-19 year old Males: 550/100,000 vs 115/100,000
- Increased survivability for younger individuals
- Lifetime costs projected $4.5 to 5 million (Livneh and Antonak, 1997) and $8 to 17 million (Bilmes, L, 2007)
$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


DeJong, G. Disability and Future Healthcare Needs, Archives of Physical Medicine, May-June 1997, V76 (3)

Emerson, E. Poverty and people with intellectual disabilities, Mental Retardation and Development Disabilities Research Review, 2007, 13 (2): 107-113

Resources


Resources


Leopold, A. Post Acute Rehabilitation of Adults with TBI: Receipt of Services, Unmet Needs and Barriers to Receiving Services, JBS International Inc., Washington, D.C. October 9, 2013 (Southwest Disability Conference)


Resources


Sanders, A. Family Response to TBI, Baylor College of Medicine Press, Dallas, TX, 2003 (monograph)


