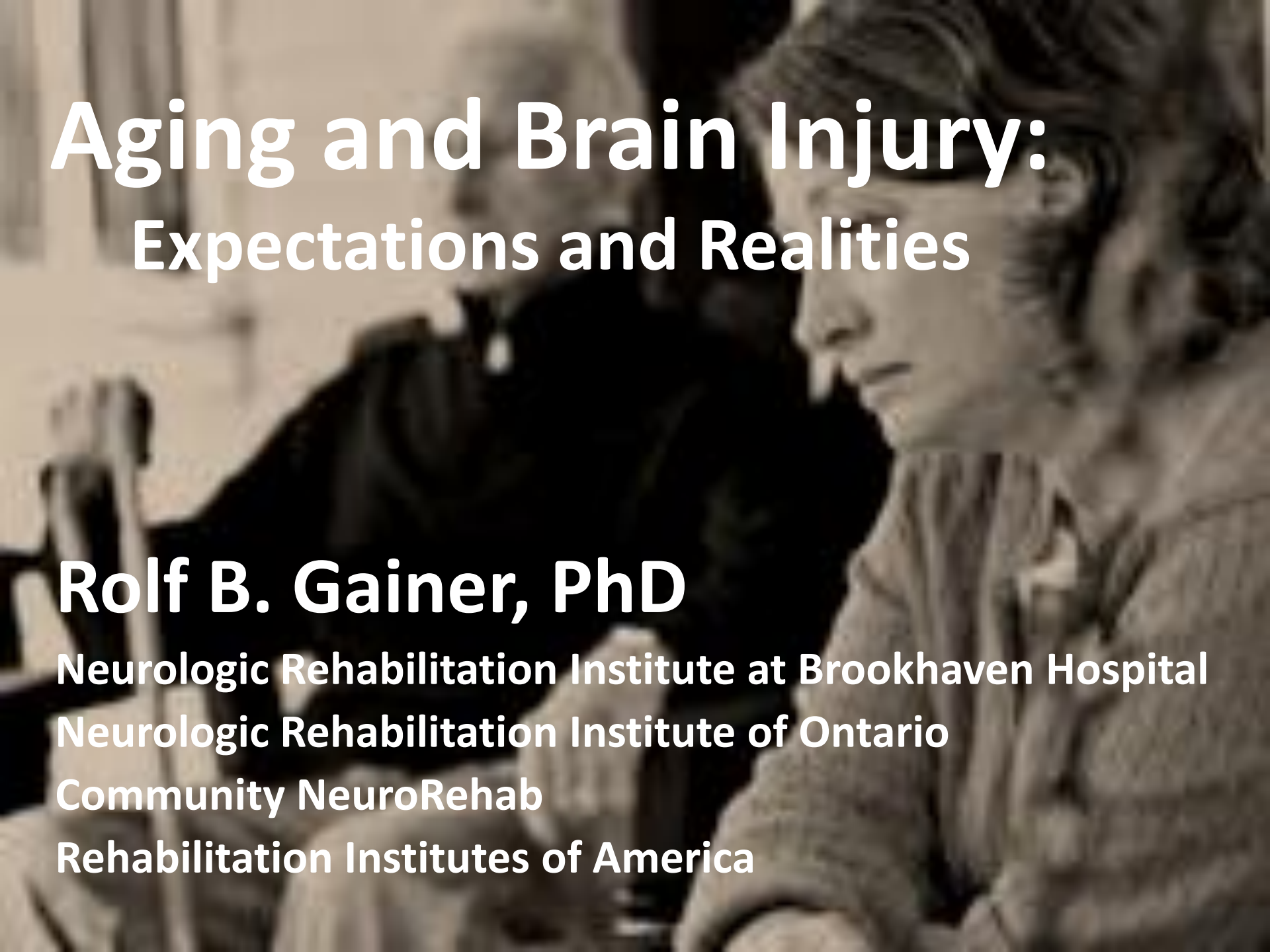


Aging and Brain Injury:
Expectations and Realities

Rolf B. Gainer, PhD

Neurologic Rehabilitation Institute at Brookhaven Hospital

Neurologic Rehabilitation Institute of Ontario

Community NeuroRehab

Rehabilitation Institutes of America

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

80 = III

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

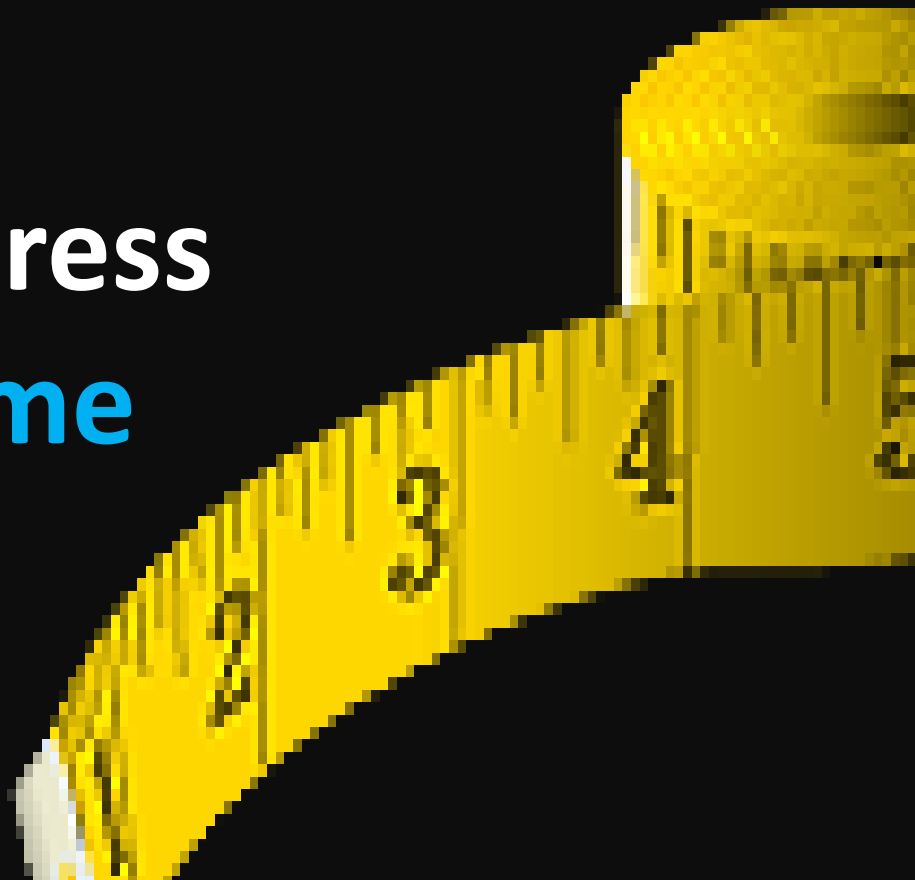
Different timeframe for onset

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


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

Source: Harrison-Felix, C., et al. (2004); Harrison-Felix, C., et al. (2006)

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

Source: Harrison-Felix, C., et al. (2009)

Health disparities and increased disease likelihood affects longevity

Creating a more vulnerable and fragile population of people aging with a brain injury

Long-term outcomes of brain injury disability

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

Source: Whelan-Goodinson, R., Ponsford, J., Johnston, L., Grant, F.J. (2009)

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

Source: Silver, J., Kramer R., Greewald., Weissman, M. (2001)

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**

Source: Fann, J., et al. (2004).

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

Source: Silverman A et al Arch Phys Med Rehabil 2015;96:1262-1268

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, 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 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

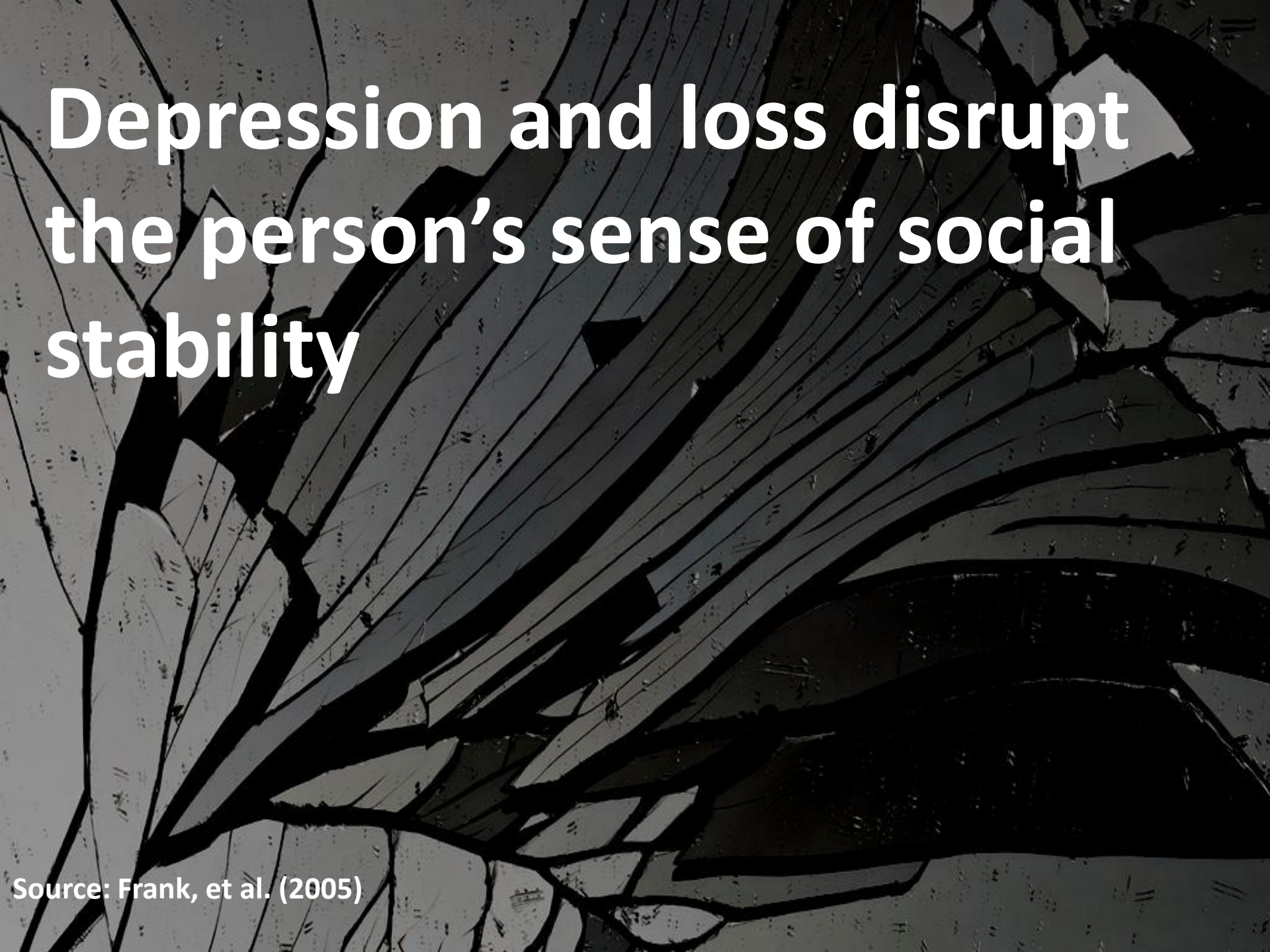
10% of an iceberg is visible,

90% is below the surface

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

Source: Masel, B. & Dewitt, D. (2010)


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).

perception of post-injury changes

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

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

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)

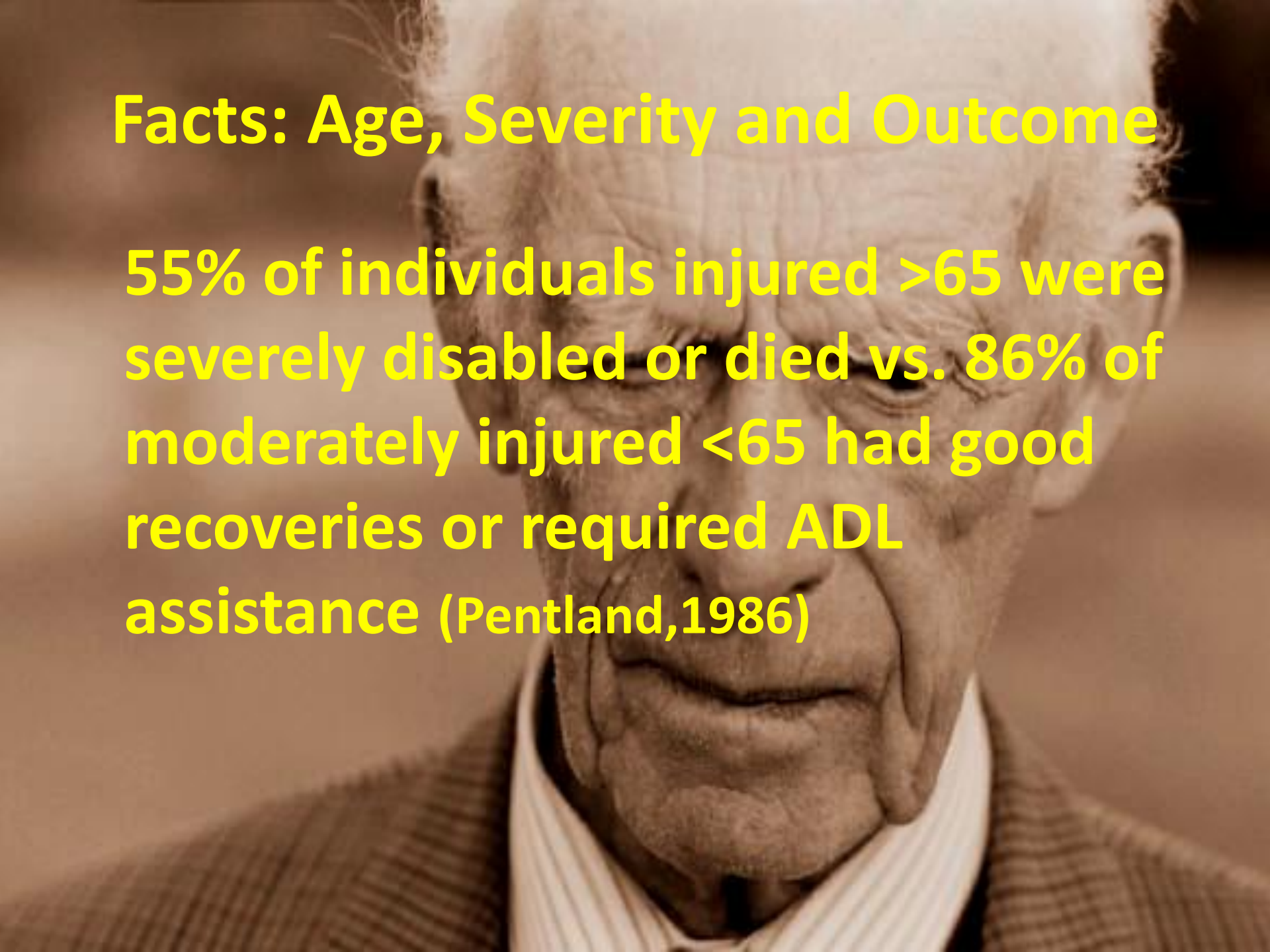
19.6%

experienced significant psychological problems requiring intervention

Source: Gainer, R., et al. (1997-Ongoing)

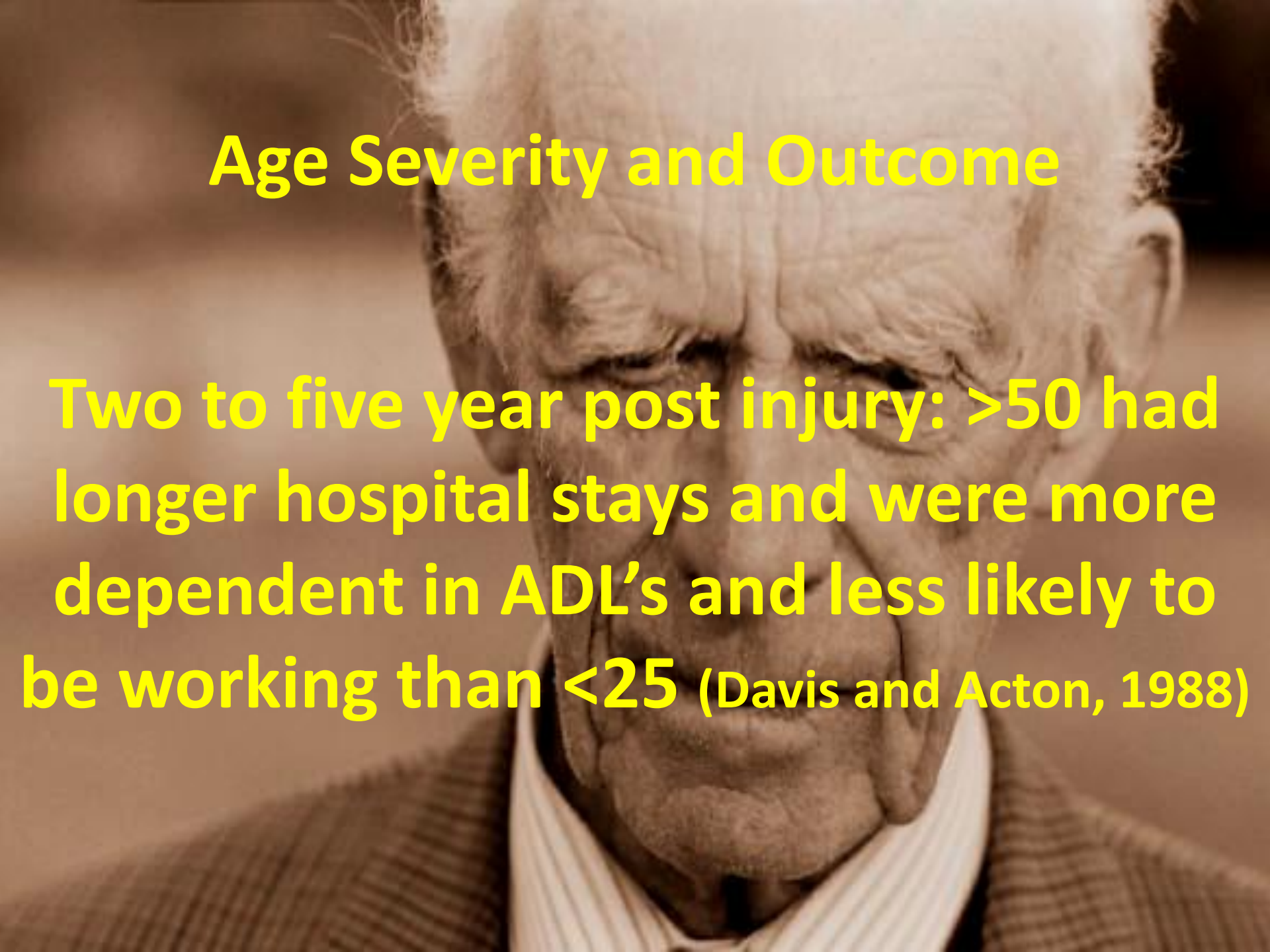
What can we **expect** of this cohort as they age?

Age and Brain Injury:
Outcomes of Injury



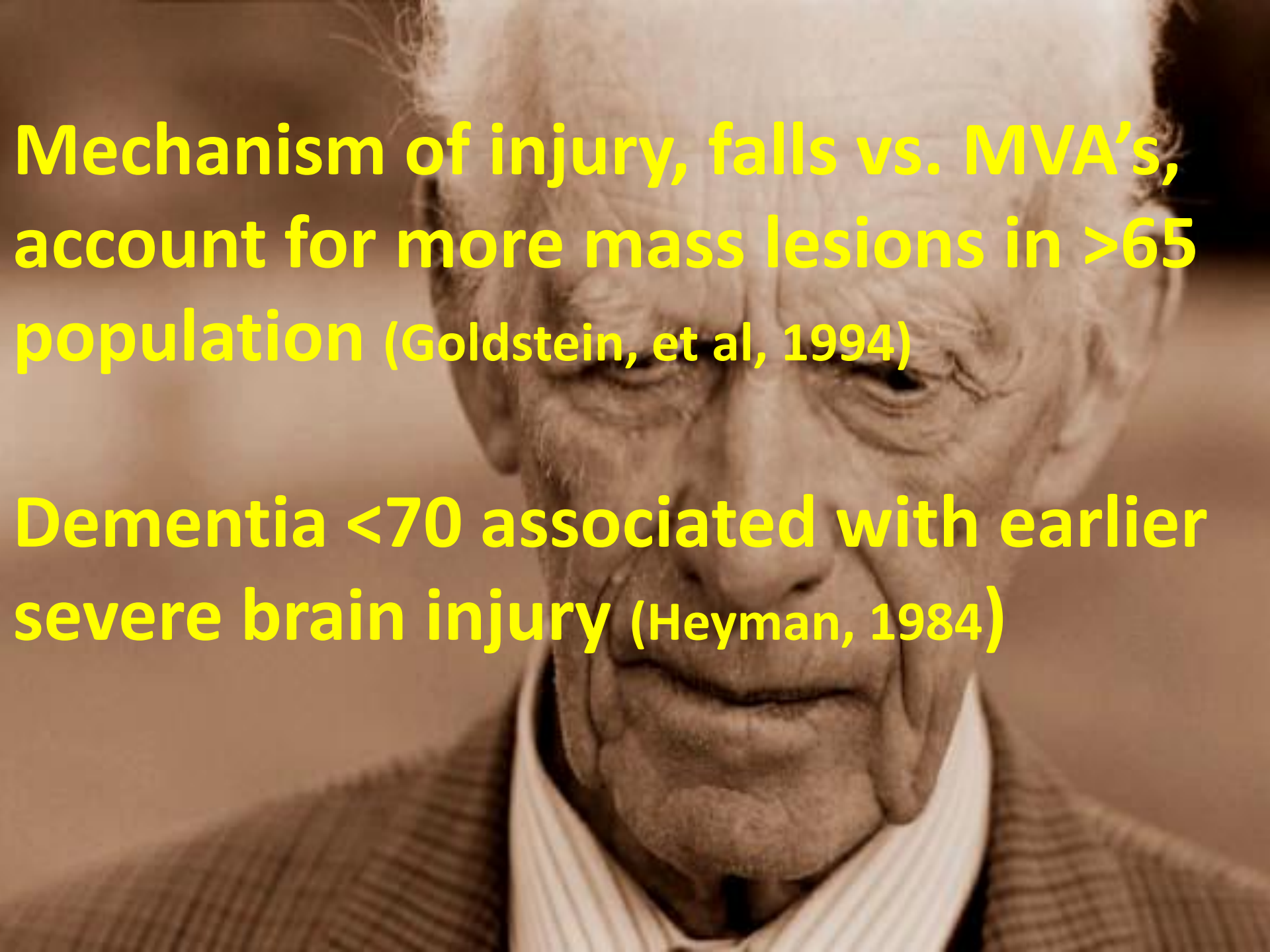
Facts: Age, Severity and Outcome

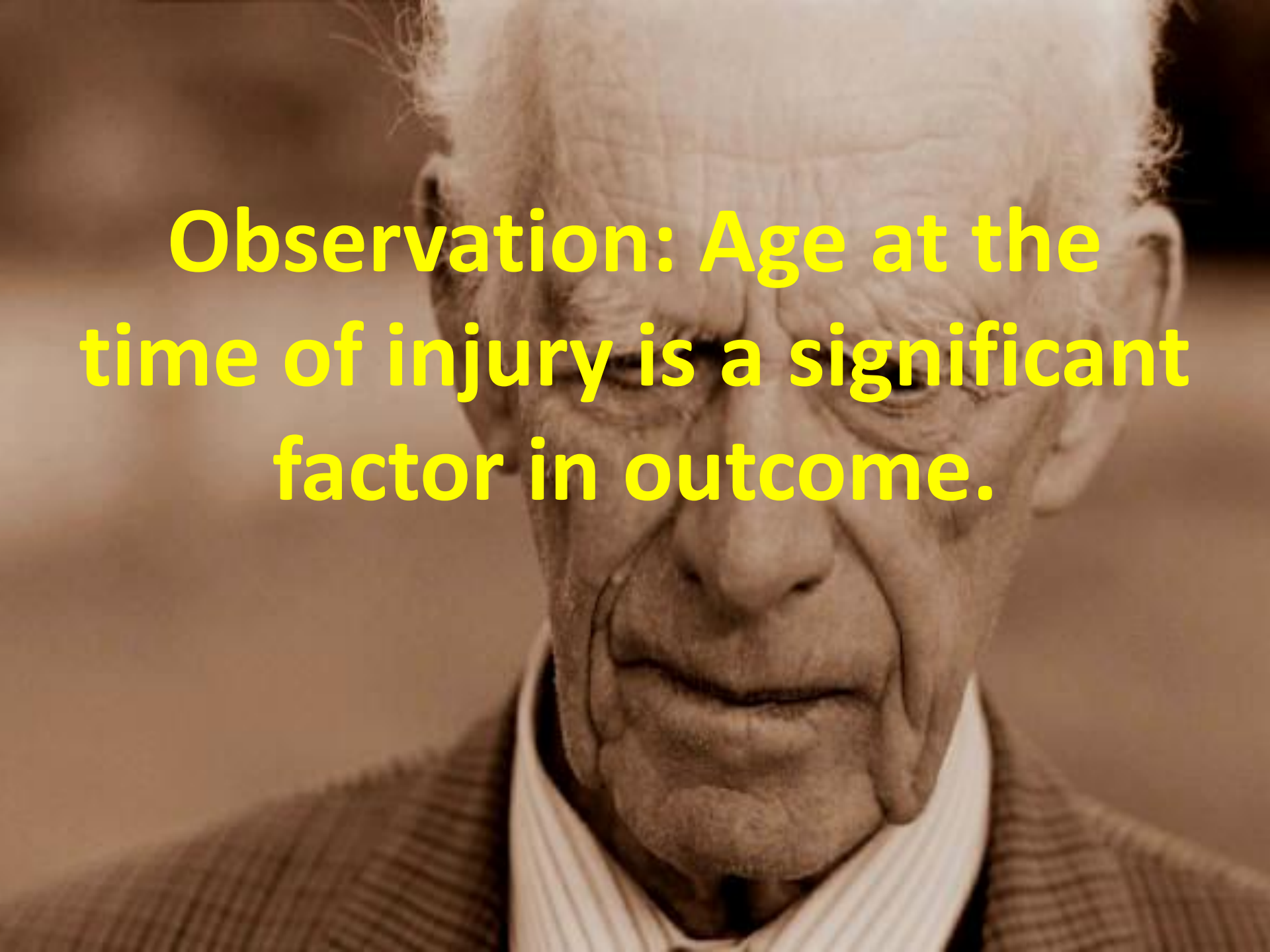
55% of individuals injured >65 were severely disabled or died vs. 86% of moderately injured <65 had good recoveries or required ADL assistance (Pentland,1986)



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 ?

physical functions

cognitive ability

interference of symptoms

ability to self-manage

How does that appear over the course of time?

son

father

wife

daughter

Meet Walter at 55

Walter at 65

son

father

ex-wife

wife

daughter

Walter at 55

aging
caretaker

community

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. 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.**

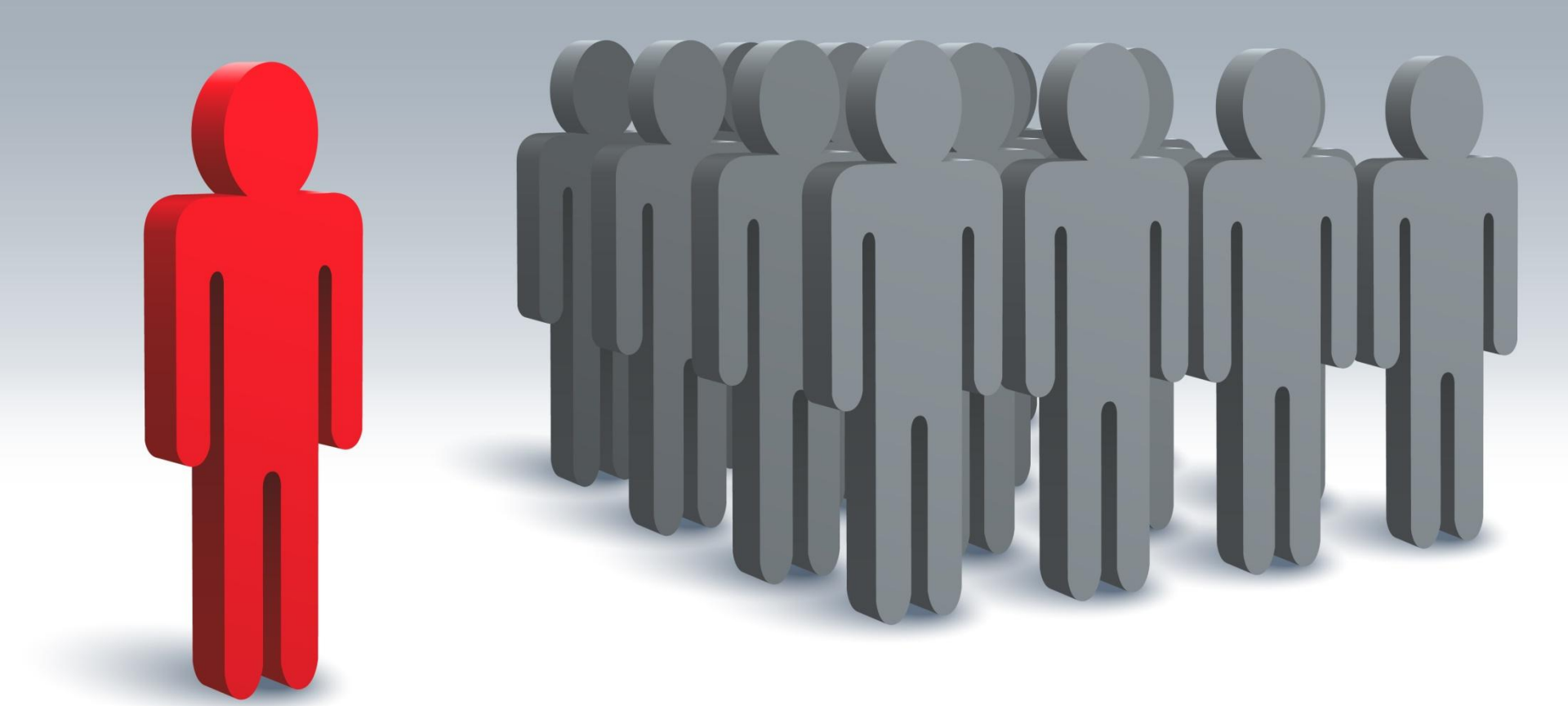
(*Source:Evercare Survey of the Economic Downturn and Its Impact on Family Caregiving; National Alliance for Caregiving and Evercare. March 2009)*

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.

(Source: Elissa S. Epel, Dept of Psychiatry, Univ of Calif, SF, et al, From the Proceedings of the National Academy of Sciences, Dec 7, 2004, Vol 101, No. 49.)

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
- 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 &
social withdrawal
stifle interaction

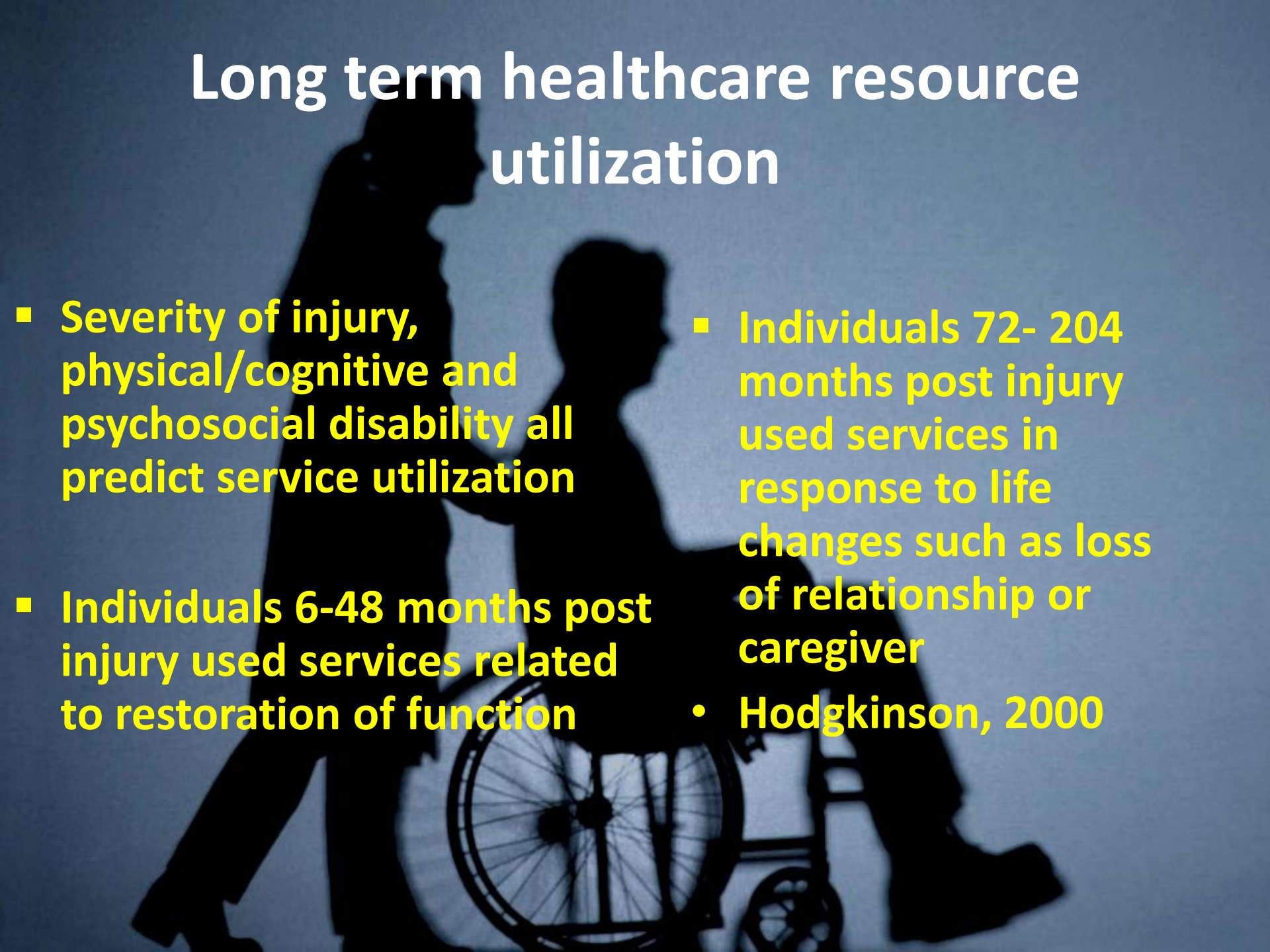
aging
hides
TBI

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

- **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

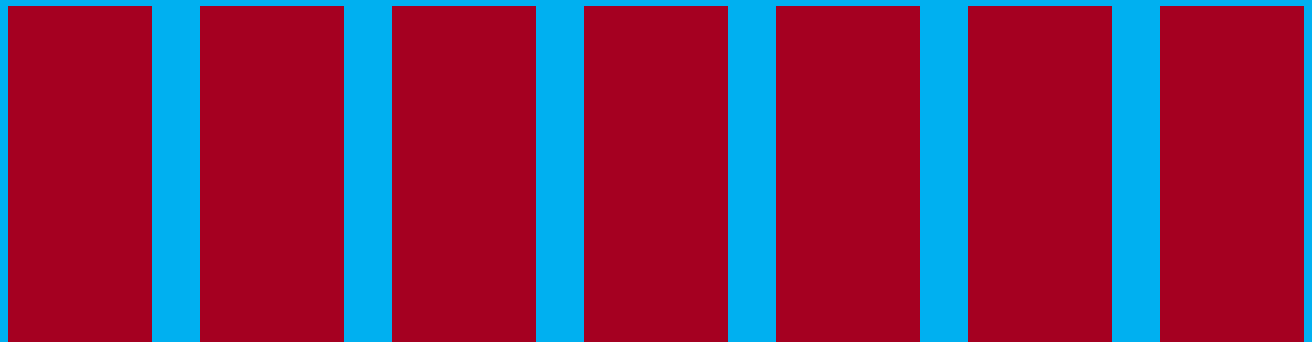
- TBI costs associated with acute care increased at twice the rate for general medical care (Kreutzer, 2001)
- Increased motor disability associated with total charges (Vangel, 2005)
- Coping and adaptive strategies learned in rehabilitation fail as individuals become middle aged and senior citizens 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
- 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: How can we address the long term needs of people living with TBI

- Increase availability of accessible housing, transportation and community supports
- Eliminate healthcare disparities
- Provide economic supports and income supplements to avoid disability based poverty

Aging and Brain Injury: How can we address the long term needs of people living with TBI

Provide lifetime supports for caregivers and family members

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

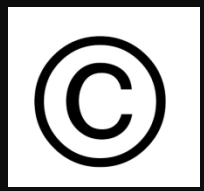
How do you address the problems associated with aging with a brain injury?

Thank you!

This presentation can be downloaded at

traumaticbraininjury.net

Look under “Resources” on the header, then “Community Presentations”



Resources

Dawson J, Chipman, L. (1995). The Disablement Experienced by Traumatically Brain Injured Adults Living in the Community, Brain Injury, (4): 339-354

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

Fann J, Burington B, Leonetti A, Jaffe K, Katon W, Thompson R. Psychiatric Illness Following Traumatic Brain Injury in an Adult Health Maintenance Organization, Arch of General Psychiatry. 2004; V 61, Jan 2004: 53-61

Resources

Fremstad, S. Half in ten: Why taking disability into account is essential in reducing poverty and expanding economic inclusion, Center for Economics and Policy Research, Washington, DC 2009

Gainer, R., et al., (1997 – ongoing). NRIO outcome validation study. NRIO, Etobicoke, Ontario.

Geurtsen, G., et al. (2010). Comprehensive rehabilitation programmes in the chronic phase after severe brain injury: A systematic review Journal of Rehabilitation Medicine, 42, 97-110

Harrison-Felix, C.L., Whiteneck, G.G., Jha, A. (2004). Mortality following rehabilitation in the Traumatic Brain Injury Model Systems of Care. Neurorehabiliation. 19(1), 45-54.

Harrison-Felix, C.L., Whiteneck, G.G., Jha, A. (2006). Causes of death following 1 year postinjury among individuals with traumatic brain injury. Journal of Head Trauma Rehabilitation, 21(1), 22-33.

Harrison-Felix, C.L., Whiteneck, G.G., Jha, A., Devivo, M.J., Hammond, F.M., Hart, D.M. (2009). Mortality over four decades after traumatic brain injury rehabilitation: a retrospective cohort study. Archives Physical Medical Rehabilitation. (9), 1506-1513.

Resources

Harrison-Felix, C.L., Whiteneck, G.G., Jha, A., Devivo, M.J., Hammond, F.M., Hart, D.M. (2009). Mortality over four decades after traumatic brain injury rehabilitation: a retrospective cohort study. Archives Physical Medical Rehabilitation. (9), 1506-1513.

Kaponen, S., Taiminen, T., Portin, R., Himanen, L., Isoniemi, H., Heinonen, H., Hinkka, S., Tenovuo, O. Axis I and Axis II Psychiatric Disorders After Traumatic Brain Injury: A 30-Year Follow-Up Study (2002) American J Psychiatry. August 2002;159,82: 1315-1321

Kim, E. et al. Neuropsychiatric Complications of Traumatic Brain Injury: A critical review of the literature. J. Neuropsychiatry and Neurosciences, V 19 (2) Spring 2007

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)

Masel, B., DeWitt, D. (2010). Traumatic brain injury: A disease process, not an event. Journal of Neurotrauma., 27(8), 1529-1540.

Ponsford, J, Draper, K, Schonberger, M. Functional outcome 10 years after traumatic brain injury: its relationship with demographic, injury severity, and cognitive and emotional status. J of the Intl Neuropsych Society 2008; 14: 233-242

Resources

Rui Fan, et al., (2013). Most Influential Emotions on Social Networks Revealed. MIT Technology Review.

Rao, V, Lyketsos, C., Neuropsychiatric Sequelae of Traumatic Brain Injury, Psychosomatics, V 41 (2) March-April 2000: 95-103

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

Sendroy-Terrill M, Whiteneck G, Brooks C. Aging with Traumatic Brain Injury: Cross-Sectional Follow-Up of People Receiving Inpatient Rehabilitation Over More Than 3 Decades. Arch Phy Med Rehabil, V 91, March 2010 pp489-497

Silver J, Kramer R, Greenwald S, Weissman M. The association between head injuries and psychiatric disorders: findings from the New Haven NIMH Epidemiologic Catchment Area Study, Brain Injury, 2001, V. 15, No. 11: 935-945. Reproduced with permission from Informa Healthcare.

van Reekum, R., Boago, I., Finlayson, M.A., Garner, S., et al. (1996). Psychiatric disorders after traumatic brain injury. Brain Injury, 10 (5), 319-27.

van Reekum R, Cohen T, Wong J. Can Traumatic Brain Injury Cause Psychiatric Disease, J. Neuropsychiatry. 2000; 12: 316-327

van Reekum R., Stuss, D.T., Ostrander, L. (2005). Apathy: why care? *Journal of Neuropsychiatry and Clinical Neurosciences* 17(1):7-19.

Yeo, R., Moore, K. Including disabled people in poverty reduction work: “Nothing about us, without us”, World Development, 2003 V 31 (3): 571-90

Whelan-Goodinson, R, Ponsford, J, Johnston, L, Grant, F. J of Head Trauma Rehabilitation. Psychiatric Disorders Following Traumatic Brain Injury: Their Nature and Frequency. 2009 Vol 24 (5): 324-332