“The New Normal”
What Really is an Outcome from Brain Injury?

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what’s the process of determining outcome?

are outcomes consistent from person to person?
“create a new baseline and not go back to where they were”

Alya Reeve, MD, University of New Mexico Hospital
From: “Every 21 Seconds or why I scream at the refrigerator”
A film by Laura Napier and Doug Claybourne, New Mexico Brain Injury Advisory Council, 2006
Goals:

• To consider outcomes as dynamic and evolving in the years post-injury
• To re-evaluate the concept of “normal”
• To conceptualize brain injury as a disease with multi-system impact
What are outcomes?

When do outcomes occur?
outcome:

• something that follows as a result or sequence

• Synonyms: aftereffect; aftermath; backwash; conclusion; consequence; corollary; development; fate; effect; outgrowth; product; result; sequel; sequence; upshot
what’s “normal”?
normal:

- according with, constituting or not deviating from a norm, role or principle occurring naturally
what’s normal after a brain injury?
who determines what’s “normal”?
When is “normal” reached?
is there a **typical** brain injury?

**no more likely than**

**there is a typical person!**
let’s consider
what’s happened to the person?
what’s going to happen to them in the future?
what is realistic?

how do we get there?
life changes.
Are outcomes fact or expectations?
what time table are they on?
tomorrow? next week? next month? next year?

exactly when will things go back to normal?
but, what’s normal?
when should we measure outcomes?
what are we really measuring?
at the time of the injury?
at the beginning of emergency medical treatment?
“heaven and hell existing within”

from: Every 21 Seconds or Why I scream at the Refrigerator
after the ICU?
what about “the chain of miracles”? does that effect our perception of reality?
emerging from crisis

- Will he live through the night?
- Open his eyes?
- Walk?
- Talk?
- Go home?
- Go back to work?
- Be the person I know?
“waking up different”

from: Every 21 seconds or why I scream at the refrigerator
could that be too early?
do we start making decisions about the person’s “return to normal” while they are in the acute medical phase?
why not wait?
but, when?
at the start of rehabilitation?
at the end of medical rehabilitation?
at the end of post-acute rehabilitation?
on the return to home?
or at.... 6?.... 12 months?
1 year...... 5 years.....
10 years?
do outcomes change over time?

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

..just like in everyone’s life
what’s normal can change, too
over the course of time
how can we learn to measure at multiple points in the lifespan?
to accurately address changes over time
What parts of me will adjust after a brain injury?
What parts of me will change after a brain injury?
how can we expand the domains we measure to be more relevant to the person and their life?
1 to 5 years after the injury

client perception of post-injury changes

nrio outcome study, adult cohort

1997-2010
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?
are aspects of outcome dependent on the person’s capacity to return to their pre-injury social roles?
are aspects of “outcome” dependent on social network participation?
are outcomes determined by the perception of deficits? whose perception?
is there an identity of disability?
can a person change that identity?
are outcomes influenced by expectations of change?

whose expectations?
how can we extend our view of outcome to encompass social role and participation?

how would we measure that?
Meet Rick at 22

mother

grandparents

best friend

art school
Rick at 22

Richard at 37

art school

grandparents

best friend

mother
social role: its bigger than we thought?
how does the person’s return to social role effect outcome?
does the return to social network participation determine outcome?
what if you don’t fit? where do you go?
what about social role return?

is it a determinant of future mental health problems?
brain injury creates a risk for a mental health trajectory

- age at onset of disability
- male vs. female
- low/reduced social supports
- financial hardships
does age at injury relate to long term emotional outcomes?

are people injured as children at a greater risk for problems later in life?
does aging change outcomes?
does stress impact on outcome?
What are we really measuring?
are we measuring against the pre-injury person?
against societal norms and expectations?
or the person post-injury?
or our personal bias and expectations?
but, before we get to measuring outcomes, we need to consider a basic question……..
Is Brain Injury a:

Sickness or disease?
does it ever go away?
a broken arm heals.....
but, a brain injury impacts for life
WHO definition of chronic disease

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

- World Health Organization, 2002
different outcomes......

are based on many factors
person-focused factors

- type of injury
- severity
- location
- the person’s recovery
- their psychological make-up
external factors

- treatment and rehabilitation received
- resources made available
- support network
- economic and financial
- community
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: as a *sickness*

this view isolates the injury from the entire person
it creates **expectations** of a return to the person’s pre-injury status
TBI: not a static process

- Impact on organ systems
- Disease causative and disease accelerative
- Impacts on the person over the course of time
TBI: Mortality and Death

• Moderate to Severe: Twice as likely to die

• Average reduction of life expectancy of 7 years
  • Harrison-Felix, JHTR, 2006
  • Savelle, AmJPhysMedRehab, 2001
Death from many causes:

Individuals more than 1 year post-TBI

- 37X more likely to die from seizures
- 12X more likely to die from septicemia
- 4X more likely to die from pneumonia
- 3X more likely to die from other respiratory conditions

- Harrison-Felix JHTR, 2006
Neurologic Disorders

- Post-traumatic epilepsy
  - Latency to first seizure as long as 12 years
    - Annegans, NEJM, 1998

- Visual Disturbances in 30-45% of moderate-severe TBI
  - Atkins E, Reviews in Neurologic Disease, 2008

- Subjective Sleep Disturbances in 70%
- Objective Sleep Disturbances in 30-45%
  - Masel and Schneibel, APMR, 2001

- Neuroendocrine Disorders 30% of moderate-severe TBI’s >1 year
  - Schneider, JAMA, 2008
Musculoskeletal Dysfunction

- Spasticity
- Muscle contractures
- Tissue Breakdown
- Skin ulceration
- Heterotopic ossification, included delayed onset and ankylosis

- TBI Medical Treatment Guidelines, Colorado Department of Labor, 2006
Incontinence

- Of 1000 individuals 5% at 1 year post injury
- Of 116 moderate-severe TBI’s >1 year 14% incontinent of bowel
- Cause of skin infections and decubitus ulcers
- Fox-Orenstein, APMR, Feb 2003
- Safaz, Brain Injury 2008

- Increases care needs
- Interferes with independence
- Interferes with community mobility and access
Psychiatric Disease with long term TBI

- Psychosis 20%
- Depression 18-61%
- Mania 1-22%
- PTSD 3-59%
- Aggression 20-40%

- TBI is associated with high rates of suicide ideation, suicide attempts and completed suicide

Kim E, JNeuropsychiatry, 2007
Psychiatric Issues: The Long Term View

- 60 individuals who were 30 years post-TBI
- 50% developed a major mental disorder after TBI
- 20% developed a personality disorder after TBI
  - Koponen S, Am J Psychiatry, 2002

- Likelihood of psychosis becoming apparent in the 2nd and 3rd years post TBI
  - Inst. Of Medicine, Gulf War and Health, 2009
Risk of Neurodegenerative Disease

- Increased risk of Alzheimer’s type Dementia - risk increases to 4X at the severe range
  - Gottlieb, S, BMJ, 2000
  - Consentino, Arch Neurolm 2010

- Post-recovery cognitive decline - 27% showed cognitive decline from baseline to 2-5 year interval
  - Till, APMR, 2008
  - Greenberg, APMR, 2008

- Other risks include Chronic Traumatic Encephalopathy (CTE)
- Parkinsonism
  - Bowers, Neurology, 2008
Cognitive, behavioral and emotional changes

- Higher incidence of cognitive, behavioral and emotional changes at 5 years than 2 years
- 32% of those working at 2 years were unemployed at 5 years
  - Olver J, Brain Injury, 1996
“The tragedy of the human brain is that it is aware of what it has lost and where it is headed—both at the same time”

Walter Mosley, “When the Thrill is Gone”, 2011
WHO World Report on Disability

- Relationship between disability and poverty
- Increased vulnerability of women, children and persons with mental health disabilities
- Increased risk for poor health
- Barriers to care

- World report on disability, 2011. World Health Organization
  www.who.int
vulnerabilities create barriers to outcome
factors **external** to the person influence outcome
are caregivers a factor to consider in outcomes?
Caregiver Stress: Factors in Long Term Outcomes
greater stigma associated with caregivers of persons with visible physical or neurobehavioral problems
increased caregiver strain leads to **social isolation, depression and anxiety**
Perceived discrimination against the person with TBI associated with increased caregiver strain and isolation

caregiver stress and community integration
greater caregiver perceived social support was associated with better outcomes in social integration
how does money impact on outcome?
is money a factor to consider in outcomes?
$15 million over the course of a person’s lifetime
who really pays?
what happens over the course of time?
10 years after the injury and rehab

nrio outcome study 1997-2010
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
19.6%

is this the cohort where we see the long term problems with social network return?
is this the group where outcomes don’t meet expectations?

whose expectations?
do **psychological** issues prevent social membership participation?
does brain injury create the perfect storm for loneliness?
is loneliness contagious?

• Average person experiences loneliness 48 days a year
• Having a lonely friend can add 17 days of loneliness
• When feelings of loneliness emerge, those feelings are transmitted to others
• Loneliness can destabilize a social network before the individual moves towards the fringe

loneliness: not a single entity

- **Social loneliness**: absence of involvement in a social network
- **Emotional loneliness**: absence of an important attachment or the loss of a relationship (Weisz, 1973)
- **Life transitions** can provoke loneliness (Marangoni & Ickes, 1989)
Predictors of loneliness in disability

• Physical dependence
• Anxiety in social situations
• Impaired social skills

• Source: Begin, G. Disability Related Variables Associated with Loneliness Among People with Disabilities. J. Rehabilitation, July 2001
Is isolation a bigger factor than disability?
factors related to loneliness

- Depression, anxiety, low self esteem (DiTomasso & Spinner, 1997)
- Suicide, suicide fantasies, alcohol and drug use (WcWhirter, 1990)
- Poor social skills (Morie, Boisvert, Loranger & Arcand, 1996)
- Poor health (Hojat & Vogel, 1987)
- Heavy users of Emergency Departments (Andren & Rosenquist, 1985)
do difficult behaviors become the person’s way of creating social engagement?

do we respond to the behavior rather than the person?
isolation, withdrawal and loneliness impact on the potential outcomes?
old questions:

derived from Frederick A. Fay, Ph.D.
what is wrong with you?
how do we fix you?
what can we do with you if we can’t fix you?
do the old questions increase the likelihood of negative outcomes?
can we change how we perceive outcomes by examining the questions we ask?
how can we consider outcomes which really help the person?
how did we get stuck in the medical model of disability from the 1960’s?
what would we say in the new questions?
how do we help define real outcomes?
how can outcomes reflect the person’s goals? values? personal choices?
can better connections improve outcomes?
how can we help facilitate social network membership?
do we allow outcomes to evolve with the person over the course of time?
or, do we get stuck with the measurement that was made following the injury?
can we learn to measure at multiple intervals throughout the person’s lifetime?

to accurately address changes which occur over the course of time
maybe we should stop measuring with old tools?
can new questions improve outcomes?
how can we help the person discover and move towards a better future?
how can we offer assistance that promotes valued experiences for the person?
how can we offer needed assistance in ways that support and sustain community participation?
how should we consider outcomes which really help the person?
Questions....... Comments?
Thank you!
“The New Normal”
Outcomes of Brain Injury and the Lifespan

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this presentation can be accessed on traumaticbraininjury.net
look under resources

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