Social Role Return Following Brain Injury: Sustaining Realistic Outcomes

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“....He is a different person than before. He used to be intelligent, motivated, outgoing and romantic - but now he is none of those things…”  Nadia, 2008
Social Role Return Following Brain Injury: Sustaining Realistic Outcomes

- Learning Objectives:
  - To develop an understanding of social role return following TBI
  - To examine the neurological and psychosocial components of social role
  - To identify the barriers related to the person and to the social system which influence social role return following a disability
  - To examine social role return issues across the lifespan
“….hospitals don’t help people, people do…..”

Elvin Semrad, “On Becoming a Therapist”, 1953
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
What happens in the years after rehabilitation is over?

- 1 Year?
- 5 years?
- 10 years?
- Lifetime?
Four Outcomes for Living: What are the affects of a brain injury?

- **Job**: 76% are unemployed
- **House**: 6.1% own their own home includes pre-injury home ownership
- **Ride**: Majority are not driving
- **Friend**: Friendships are lost following TBI

- The measures of “normalcy” are affected
Social Network Components

- Family
- Primary Relationships
- Friends
- Work
- Community

- All aspects of our social network require participation
Components of “Self Worth”

- Job, profession, skills
- Relationships, Family, Friends
- Life Activity Focus
- Home, residence ownership
- Membership in community
- Perception of individual by others/ positive feedback
- Participation with others in activities of value
The “I” function and social role return

- Capacity to maintain a sense of self
- Relating abilities
- Capacity to initiate behavior/activity
- Ability to respond/reciprocate
- Recognition of self among others
- Maintaining the “Social Rhythm”
Brain based determinants of social role behavior

- Theory of Mind concepts (Stuss, Henry, Bibby and McDonald)
- Emotional recognition
- Infer mental states of others
- Social Cognition
- Cognitive Flexibility
- Executive Functioning

Is our social role functioning determined by frontal lobe function?
Is self-worth a factor of “social capital”

- The value of a person is created by the individual and their society
- The roles a person occupies and their effectiveness in those roles creates value
- Disability and loss of role function produces a decline in self-worth as perceived by the person and others
  - Source: Condelucci, 2007
- Depression and loss disrupt the person’s sense of social stability
  - Source: Franks, et al 1996
Apathy and Social Role Return

- Individual may not fully sense their altered role behaviors and performance
- Ability to participate in relationships is reduced
- Significant response by others to changes in functional status ("...not the same person...")
- Loss of responsiveness to requirements of role
- Lack of initiation of behaviors integral to role
Apathy: Who Cares?
Is social role function determined by injury location?

- Apathy found in adult TBI at a prevalence range of 46.4% to 71.1%, average of 61.4%
- Loss of role and hopelessness found in most individuals with apathy
- Apathy may not be concern to the individual due to a loss of self-observation
- Caregivers rate apathy as the third most difficult neurobehavioral problem
- Apathy is associated with a reduced emotional and physical response
- 83% of TBI cases with apathy had comorbid depression
- Differentiation of “social apathy” an altered sense of self and social awareness related anterior frontal lesions
- Apathy may exist as subtypes defined by frontal-subcortical loops (Apathy Syndromes)
- Source: Van Reekum, Stuss, Ostrander, 2005.
Examining the Barriers to Social Role Return: Years 1-5 Post TBI

- Social behavior and judgment problems causing legal problems (range 9-33% of cases)
- Post injury substance abuse (range 9-36% of cases)
- Problems with spouse/significant other (range 22-45% of cases)
- Problems with relating to/maintaining friends (range 50-88% of cases)
- Source: NRIO Outcome Validation Study 2007
Social Role: A network of mutuality built on participation

- Disability creates an exclusion from network
- Mutual relationships shift
- Social isolation and exclusion occurs
- Connectivity vs. disconnection
- Isolation is enforced by problems preventing access and by time
- Aging further enforces the isolation and exclusion related to disability

Social role is defined by relating to others
What can we learn about the effects of TBI disability on the social network and social role?

- The effects over time
- The reduction in size and complexity
- The “distancing effect”
- The loss of “interpersonal connectivity”
Ten Years Later: A Shrinking and Aging Social Network

- Rick Pre-Injury
  - Rick (22) + Girlfriend (20) +
    - Mother (49) +
    - Grandmother (79) +
    - Grandfather (80)
  - Best Friend Charlie (23) + Al (27) + others
  - Art school + band

- Rick 15 Years Post-Injury
  - Rick (37) + Mother (64)
  - Charlie (38)
Ten Years Later: A Changing Social Network

- **Cherri Pre-Injury**
  - Cherri (32) + Bob (35) + Paul (10) + Susie (5)
  - Mother (58) + Grandmother (81) + Grandfather (81)
  - Cherri’s friends
  - Church + social group membership
  - Cherri’s co-workers

- **Cherri 10 Years Post-Injury**
  - Cherri (42) + Mother (69)
  - Cherri’s friends
  - Bob (45) + Susie (15)
  - Paul (20)
  - Church
TBI as the Index Event and changes over time affect social role reintegration

- Loss of skills, capacities and ability to participate in life activities
- Loss of primary relationships
- Isolation from friends, work and community
- Death/illness of family and caregivers
- Distancing of others from the individual
- Aging, situational change
- Additional changes in ability to participate
- Increase in medical problems and complexity over time
The Social Network: Degrees of Separation

- Primary Relationships
- Children grow up
- Friendships
- Parents age/death
- Social participation declines
- Community participation fades
- Ability to work changes
Social Network, Aging and Disability

- Restrictions to access
- Limited resources
- Aging of family caregivers
- Aging of the individual
- Social isolation
- Earlier onset of medical problems
- Moving away from family and friends
- Changes in home and community
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 1997-2007; NRI Outcome Study 1993-2006
Do the changes to the survivor population affect what long term outcomes are attained?

- Increase in surviving with greater severity of disability
- Living with multiple disabilities and complex medical problems
- Living longer with disabling conditions
- Requiring more resources and supports
- Experiencing economic changes
The Value of Contributing: The Myth of Independence

- “Giving vs. Taking”
- Misconception of independence vs. being involved with others in cooperative ventures and activities
- Shift created by disability
- Impact of altered functional status on self image and value of self
Care needs and social isolation

- Study involved 454 Canadians, average 13 years post TBI
- 66% required ADL assistance
- 75% not working
- 90% dissatisfied with social interaction
- 47% not talking with others by telephone
- 27% never socialize at home
- 20% never visit others
- Source: Dawson and Chipman, 1995
Economic factors associated with aging with a disability

- Living with a disability requires financial resources. The process of aging may place additional demands on the already limited financial resources and exert pressure on the individual and their family effecting all aspects of life.

- Disability Related Poverty places additional barriers on social role return
Brain Injury Disability and Health Disparities

- Economic and social status affect health status
- Poor health practices due to cognitive problems
- Limited resources/insurance for healthcare
- Reduced health literacy due to cognitive problems
- Increased rates of: obesity; hypertension; depression; diabetes
- Increased stress

Sources: Williams, David, 2006; Willis, Diane, 2002
Health Literacy and TBI Disability: Problems with Maintaining “Wellness”

- Follow healthcare and wellness regimes
- Follow directions for prescription/ non-prescription medications
- Understand “side effects”/ interactions of medications
- Report problems to physician
- Be able to organize and discuss healthcare status
Gender based disparity in healthcare access

- Women with disabilities more likely to postpone health care
- Transportation difficulties
- Scheduling appointments
- Women with disabilities have less access than women without disabilities and men with disabilities
- Education, race/ethnicity and age further affected access to healthcare

Source: Smith, Disability and Health Journal, 1, 2008
Support and care needs increase

- As functional abilities decrease over the course of a person’s life they will require more support from family and paid caregivers.

- Desire to return to the community does not change, but the increase in medical complexity serves to maintain placement outside of the community.

Source: Karon and Lazarus, 2008
Neuropsychiatric Features of Brain Injury

- Psychosis
- Depression
- Anxiety Disorders
- Mania/ Affective Disorders
- Post Traumatic Stress Disorder
- Aggression
- Irritability
Brain Injury as an Accelerant to Psychiatric Conditions

- Thinking problems
- Executive dysfunction
- Emotional response to injury and disability
- Difficulties with self-regulation and impulse control
- Memory problems
- Compliance with treatment
- Social withdrawal
- Social role changes and isolation
Co-occurring diagnoses complicate recovery

- Clinically significant depression in 57%, excluding substance abuse and pre-injury problems (Douglas and Spellacy, 2000)
- Anxiety and depression in 50% of severe TBI (Anson and Ponsford, 2006)

- Depression found in 44% of cases over a 7.5 year period (Van Reekum, 2000)
- TBI increased risk for bipolar disorder, OCD, panic disorder and PTSD
- Depression found in 61% of TBI cases average more than 7 years post injury (Hibbard et al, 1998)
Coping Styles Determine Adjustment to Disability and Long Term Outcome

- **Two Distinct Style**
- **Type 1**: avoidance, worry, wishful thinking, self-blame, alcohol/drug abuse
- **Type 2**: actively working on problem, using humor, finding enjoyable activities to manage stress

Source: Curran et al, 2000
Mental Health and TBI: Long Term Negative Impact

- Unemployment at 2, 5 and 10 years post-TBI associated with anxiety and depression (Franulic et al, 2004)

- Quality of life indicators at 14 years post-TBI are depression, participation in work/leisure, and availability of emotional supports (Steadman et al, 2001)
Behavioral and Emotional Factors of Community Re-Integration

- Loss of control (Impulsivity, aggression, mood changes and irritability) associated with low community re-integration at 8.8 years post-TBI (Winkler et al, 2006)
Increased Risk for Substance Abuse

- Pre injury factors involving substance use/abuse
- Exacerbated or emerging use post injury
- Self-medication, response to depression, mood state changes
- Boredom, loss of life focus, withdrawal and exclusion
- Family difficulties
- Loss of peer group and social network

Source: NRIO Outcome Validation Study, 1993-2007
Substance Abuse and Long Term Outcomes

- Pre-injury psychiatric and substance abuse problems predicted employment problems 2 years post-TBI (MacMillan et al, 2002)

- Co-occurring TBI and substance abuse associated with lower likelihood of working, lower subjective well-being, increased likelihood of committing suicide and greater risk for seizures (Corrigan, 2005)

- Within the NRIO Outcome Validation Study in a group of individuals, 2-5 years post severe TBI and involved in an extended care program, 36% had pre and post-injury substance abuse problems and 45% reported problems with spouse/significant other and 45% reported problems in maintaining relationships with friends (NRIO Outcome Validation Study, 2007)
Increased Risk for Suicide

- Response to depression
- Social isolation and exclusion
- Diminished impulse control/ self regulation
- Reduced problem solving ability
- Highest rates among males 15-24 and 65+
Prevalence of Suicide Attempt Following Brain Injury

- Risk increases in the first 15 year period post-injury. 17% of individuals with TBI report thoughts, plans and attempts in the first 5 year period (Teasdale, 2000)
- Social Withdrawal (Sugarman, 1999)
- Role of Executive Dysfunction (Mazaux, 1997)
- Awareness of deficits (Prigatano, 1996)
- Disinhibition, impulsivity (Shulman, 1997)
- Highest number of attempts observed in males 25-35 and 65+
- Role of Identity crisis and social disruption (Klonoff and Tate, 1995)
- Comorbidity with psychiatric or substance abuse is a common factor
- Hopeless/despair are key factors, role of Affective Disorders (Morton and Wehman, 1995)
- Increased risk for individuals with Mild TBI, psychiatric diagnosis and psychosocial disadvantage (Teasdale and Engberg, 2000)
- Increased risk due to TBI as stressful life event (Frey, 1995)
Components of Suicidal Risk Associated with TBI

- Desire to die
- Ability to engage in an act of lethal self harm
- Sense/belief that one is a burden to social supports
- Feeling/thinking that one does not belong to a valued social group or relationships
- Evidence of decreased fear of self-injury evidenced by increased risk taking, exposure to pain or dangerous activities/events

Source: Joiner, 2005
Social Role Adjustment: A Complex Process

- View of self and altered functional status
- Ability to maintain relationships
- Ability to participate in work, avocational or leisure activities
- Coping skills
- Presence of psychiatric symptoms
- Presence of substance abuse
- Availability of support network
Are the Four Outcomes of Life Realistic After Brain Injury?
Three Domains of Function and Social Role Return

- Physical
- Cognitive
- Emotional
Positive and Negative Roles

- “Positive”
  - Helper
  - Worker
  - Caregiver
  - Friend
  - Colleague
  - Peer

- “Negative”
  - Helpless
  - Unemployed
  - Care Receiver/Patient
Covert Disabilities: Lack of Precise Data

- Aging process “hides” TBI related disability
- By age 80 the average person has 3 disabling conditions
- Isolation and social withdrawal prevent interaction
- Living with aging caretakers limits access to resources and community
- Resources not available to support the individual’s independence
The process of aging with a TBI

- An accelerated aging process reduces the level of independence attained by the individual
Support and care needs increase

- As functional abilities decrease over the course of a person’s life they will require more support from family and paid caregivers.
Social Role Changes

- Social role return is a significant aspect of long term outcome which can change as the person ages and requires more assistance, care and support from others.
Diminished cognitive abilities

- Functions such as memory, decision making and problem solving may decline as the person ages and the gains made in rehabilitation will erode
Diminished physical functions

- The reliance upon others to provide care increases over time, further reducing independence and affecting the person’s ability to participate at home and in the community.
An accelerated decline caused by injury severity

- Health issues related to long term injury effects and healthcare access
- Early onset of physical and cognitive decline
- Psychological response to a long term disability
- Social exclusion and social withdrawal reduces access to care opportunities
- Potential for reduced health literacy due to cognitive deficits
Clinical Profiles: The Years Post Injury

- Status of individuals who are 10-25 years post-injury
- Loss of specific gains made in initial rehabilitation
- Onset of specific medical problems
- Increase in care needs
Brain Injury in Childhood: A prelude to future disability?
Children with TBI: Two Years Later

- 40% of the participating children required modified school programs, 20% returned to grade level participation
- 60% of the participating children re-entered school with a modified social role
- 40% of the families performed attendant care functions at the two year point
- 40% of the participating children required psychological and/or behavioral support

Source: NRIO Outcome Study 1993-2007
Long Term Outcome Issues for Children

- Development, academic and social problems
- Psychiatric, psychological and behavioral problems emerge (Max, 2004)
- Alienation from peer network
- Social adjustment problems
- Transition from family does not occur
- Isolation within family
Long Term Implications for Children with TBI

- High survival rate from moderate to severe injuries
- Likelihood of future psychiatric disorders, learning problems and psychosocial adjustment problems
- Early age at injury related to problems surfacing 5-8 years post injury
- Social isolation from peers caused by functional and behavioral issues
- Need for extended family supports
Today’s Child with TBI is Tomorrow’s Elderly

- Effects on maturational processes, long term issues associated with “Cognitive Stalling” (Campbell, 2007)
- Continued learning and cognitive problems
- Self-image and evolution of person
- Limited access to social network
- Caregiver and support issues
Growing Up with a TBI

- Loss of membership in peer group
- Prolonged dependence upon family
- Social isolation
- Limited participation
- Reduced options
- Increased likelihood for mental health problems
Mental Health Issues and Aging with a Brain Injury

- What happens to the individual with psychiatric and substance abuse issues as they age?
- Greater likelihood of crisis
- Reduced ability to self manage symptoms and required medication
- Greater interference of symptoms with functional abilities
Disability and Death of a Caregiver

- Abrupt transition in relationship, personal care, housing and healthcare routines
- Problems associated with the loss of a loved one
- Finding other family members or paid caregivers to assume care responsibilities
- Economic upheaval
The Long Term Perspective
10 Year Perspective: Social Role Return

- Over the 10+ year span of the study, an average of 37.3% report returning to and maintaining their primary social role without modification.
- 43.1% report experiencing a change in social role status requiring support from family members.
- Follow-up study observed “no regression” in social role return and noted that individuals were reassuming greater aspects of their pre-injury social roles as time progressed.

Source: NRIO Outcome Validation Study, 1993-2007
Maintaining Independence: Clients’ Perspective at the Ten Year Point

- 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

System Barriers to Social Role Reintegration

- Lack of resources for people with co-occurring disabilities
- Individuals with co-occurring problems are in more restrictive setting (psychiatric hospitals, prisons, nursing homes)
- Divergent, rather than integrated treatment results in failed reintegration and unsuccessful supports
Can we fix what is broken?

- Early recognition of barriers in the rehabilitation phase
- Training for support and caregiver systems
- Identification of resources that address the co-occurring issues
- Participation in activities that have meaning
- Development of extended supports to maintain the person in the community over the course of their life
- Correcting the issues which maintain disability related poverty and health disparity
What about the people?

- How can we support and strengthen caregiver systems?
- How can alternative living situations be developed to enhance independence and avoid institutionalization?
- How can we respond to the realistic costs of a lifetime disability?
- As the severity of disability and the number of individuals living with the long term effects of TBI increases, will there be adequate resources?
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