

# TEN YEARS LATER:

Living in the Community with a Severe Brain Injury

*presented by*

**Rolf B. Gainer, Ph.D.**  
*Diplomate, ABDA*

Neurologic Rehabilitation Institute at Brookhaven Hospital

Neurologic Rehabilitation Institute of Ontario

# What can we learn from Outcome Studies?

- Identify trends in population: what problems are similar?
- Identify characteristics associated with both “good” and “bad” outcomes
- Examine dynamics/issues which cause failure
- Identify factors which promote or sustain good outcomes
- Identify problems which occur after the injury and rehabilitation which affect long term outcome
- Compare program outcomes with other studies and other prior reports

# Parameters Studied in NRI & NRIO Outcome Studies

- Demographic Characteristics
- Severity Descriptors
- Length of prior acute & post-acute treatment
- Discharge destination/living situation needs
- Level of paid care needed at discharge
- Level of family-provided care needed at discharge
- Additional rehab needed
- Vocational return/ Avocational activity focus
- Social role return/ Degree of Role Modification
- Interfering factors: Substance Abuse, Psychiatric Issues, Medical Problems
- Community Mobility
- Durability of outcome assessed at 3, 6, 12, & 24 month intervals
- Cost benefit
- Comparison with prior periods and external studies

# What aspects of the rehabilitation outcomes were “durable” at the five- year point?

*Source: NRIO Outcome Study, 2002*

- Sustained employment declined
- Paid in-home supports declined
- Social role and social network problems increased
- Dependence on family members decreased
- Substance use increased
- Behavioral health problems remained stable

# Characteristics of NRIO Clients Over a 10-Year Period

*NRIO Outcome Study 1993-2002*

- Greater severity of injury and related conditions
- Increase in age of survivor population
- “Sicker and quicker” a shorter stay in acute medical rehabilitation with acute care issues lingering
- Shorter treatment intervals from time of injury to home/community placement
- Decreased lengths of stay in post-acute and community programs
- Increase in co-morbidity of individuals served
- Decrease in financial resources available for rehabilitation

# Returning to the Community with Complex Care Needs

*What are the long term issues that people face?*

- **Community Access**
- **Mobility**
- **Service Requirements**
- **Social role re-entry**
- **Meaningful life activities**
- **Maintenance of rehab gains**

# Five & Ten Year Benchmark Comparisons

*Source: Kreutzer, Livingston, Taylor, West, 2003*

- Study included two groups:
  - Mid-term, 5-9 yrs.
  - Long-term, 10-35 yrs.
- Most frequently cited “obstacles”
  - Memory
  - Thinking
  - Vision
  - Coordination/Moving Limbs
  - Transportation

# Most Commonly Reported Neurobehavioral Problems

- Bored
- Misunderstood
- Frustrated
- Inpatient
- Writes slowly
- Reads slowly
- Thinks slowly
- Moves slowly
- Loses balance
- Difficulty lifting heavy objects
- Tired
- Trouble making decisions
- Loses train of thoughts
- Easily distracted
- Problems concentrating

# Individuals Reporting of “Unmet” Needs Post Brain Injury

*Source: Heinemann, Sokol, Garvin and Bode, 2002*

- Assistance with problem solving: 52%
- Increasing income: 51%
- Improving job skills: 45%
- Opportunities to socialize: 42%
- Increasing education: 40%
- Managing stress: 40%
- Managing money: 35%
- Traveling in community: 15%
- Legal problems: 22%
- Independence in housekeeping/shopping: 25%
- Improving health: 30%

# Barriers: Ten Years Later

What are the issues and problems that are noted by clients and family members?

*Source: NRIO Outcome Study, 1993-2002*

- Physiological decline and onset of additional medical/health problems
- Ability to be mobile and access the community
- Social role function and integrity of the social network
- Activity focus: vocational and/or avocational
- Persisting cognitive and/or behavioral issues
- Emergence of psychiatric and/or substance abuse problems
- Problems of aging with a disability

# Quality of Life Issues: Client & Family

What are the quality of life issues faced by individuals with complex care needs once rehabilitation has ended?

- Independence vs. interdependence vs. dependence
- Social role with family, marriage and friends
- Work, recreation and high value activities
- Addressing continuing rehab and medical needs
- Coping with changes and new problems

# What are the general issues seen in individuals with complex care needs who are living in the community?

*Source: NRIO Outcome Study, 1993-2002*

- Limited physical functions
- Chronic medical care issues
- Reliance upon others for assistance with life activities
- Ability to access the community
- Role of psychological issues, such as depression
- Cognitive and behavioral consequences

# What are the community living problems that are seen in individuals with complex care needs?

*Source: NRIO Outcome Study Reports, 1993-2002*

- Limited housing choice
- Return to living with parents or family in a dependent status
- Difficulty in accessing activities outside of the home due to transportation, mobility and access problems
- Requiring multiple and coordinated supports to sustain community living
- Limited availability of programs with expertise/accommodations for TBI population

# What are the characteristics of the group with a brain injury and complex care needs?

*Source: NRIO Outcome Validation Study Reports, 1993-2002*

- GCS at Injury .... 3 (initial)
- Age at Injury..... 34.4 years
- Duration of Acute Medical Rehabilitation.... 27 months
- Gender .... 83% Males
- Education Level....60% High School, College, University graduate
- Work history....83% employed outside or inside the home, 17% retired/previously disabled
- Role of alcohol in accident....33%

# What conditions exist following discharge from rehabilitation that continue to affect community living?

*Source: NRIO Outcome Study, 1993-2003*

- Cognitive problems ranging from arousal and attention to executive functions
- Communication problems ranging from individuals not able to use communication devices to individuals who are effectively using devices or speaking
- Mobility problems ranging from individuals requiring total assist to individuals requiring less than two hours per day
- Psychological problems related to adjustment to disability, depression
- Social role issues ranged from divorce and separation to living as an adult in the home of aging parents to isolation within the family unit
- Trend of progressive social role deterioration

# What chronic medical problems exist for the individual with complex care needs living in the community?

*Source: NRIO Outcome Study Reports, 1993-2002*

- Seizure disorders
- Respiratory problems
- Swallowing disorders
- Skin integrity
- Diabetes
- Circulatory problems
- Contractures and orthopedic problems
- Stoma care/GI complications
- General health decline
- Pain Management, including headaches
- Fatigue

# What trends are occurring in the survivor population that will continue to affect community living?

*Source: NRIO Outcome Validation Study Report for 2002; D'Angelo and Laver, 2003*

- Increase in age at injury from 24 in 1993 to 34.4 in 2002
- Steady decline in length of acute medical rehabilitation stay from in excess of 40 months in 1993 to 15.8 months in 2002
- Steady decline in post acute rehabilitation period from 37 months in 1993 to 7.5 months in 2002
- Increase in the incidence of restraint use (seatbelts/airbags) from less than 10% in 1993 to 83.3% in 2002
- Decrease in Glasgow Coma Scale at time of injury and increased coma duration, overall increase in severity of injury
- Increase of alcohol as a factor in MVA injuries from 15% in 1993 to 33% in 2002 (NRIO Outcome Study, 1993-2002)

# What outcomes do individuals with complex care needs attain following rehabilitation?

How will these needs affect long term community living?

*Source: NRIO Outcome Study, 1993-2002*

- 38% require paid supports in the home more than two hours per day
- 62.5% report significant changes in a role as spouse and/or parent as well as with friends
- 62.5% regard their needs as “dependent upon family members” for basic assistance
- As injury severity increased alcohol and drug use issues decreased, but depression and psychological issues increased
- Increase in behavioral health issues such as: depression and bipolar disease following discharge from active rehabilitation programs

# Implications for Community Living

- **Impact of social isolation due to restricted community mobility and access, lack of support group availability**
- **Effect of significant social role changes through divorce, separation, dependence**
- **Continuing psychological and psychiatric symptoms related to a high incidence of depression and other behavioral health diagnoses**
- **Continuing cognitive problems' effect learning and application of skills**
- **Demonstration of ongoing needs for specific rehabilitation services**
- **Difficulty with independent management of chronic, injury related health care needs**
- **Other difficulties in family and primary relationships**

# Life After Rehabilitation: Ten Years Later

## Primary Problems Noted by Individuals and Family Members

*Source: NRIO Outcome Study Reports, 1993-2002*

- Housing problems
- Community access and transportation
- Low activity level, frustrated with quality of activities
- Emergence of additional health care problems; time spent in health management activities
- Limited knowledge of providers of long term TBI issues
- Lack of coordination between community service providers
- Limited availability of services for dual diagnosis individuals
- Lack of availability of respite or in-home relief services, a factor in “caregiver burnout”
- Economic changes
- Stresses within family, withdrawal of friends

# What's better in the community?

## *A Quality Report at the Ten Year Point*

### **Comments of clients and family members:**

- Improvement in life quality in community/home over past experiences in care facilities
- Range of choices available
- Ability to self-direct life and make decisions
- Return to family and loved ones
- Sense of independence
- “Get on with my life”

# Individual and Significant Others' View of Future Problems: *After the First Ten Years*

- Aging issues in the future
- Health issues
- Health and aging issues for the caregiver and/or the family
- Likelihood of decreased functional abilities
- Financial issues, projected future care needs
- Finding a long term environment which is appropriate
- Maintaining quality of life

# Long Term Community Living Issues

## Needs Identified by Family Members:

- Increasing need for respite or in-home supports to relieve caregivers
- Transportation to needed services
- Prevention of social isolation of the individual living with TBI and family members

# What can we learn from community living experiences to support/maintain rehab outcomes?

- Address primary relationships and social network participation
- Address caregiver burnout, aging and other factors in the social support network
- Consider how case management and coordination will occur to provide long term contacts with the individual
- Identify health care providers and rehab professionals who are knowledgeable in long term brain injury
- Provide resources for mental health supports
- Sustain access to desired activities
- Promote effective decision making

# Roles of Caregivers: Ingredients for Sustained Success

- “Roving Frontal Lobes” replacing cognitive and self-regulatory functions (Condelucci)
- Case Management, care planners, “care brokers” and organizers
- Mobile support personnel/group
- Re-inventing family and primary relationships
- Sustaining focus and motivation

# Future Trends

- **Increase in injury severity of survivor group, increased coma duration, greater multi-system involvement**
- **Decreased rehabilitation period in acute medical and post-acute community-based phases**
- **Increase in age at injury, proximity to aging issues**
- **Family stressors enhanced by aging issues**
- **Access to and adequacy of services available in the community**
- **Limited financial resources, increased demand for public monies/programs/services**

# Future Trends (continued)

- **Need for expansion of services into rural and less populated areas**
- **Need to identify links in the continuum of care that support transitions from hospital to home and community**

# What does the future hold for individuals with severe, lifelong disability problems associated with complex brain injury?

- How can we improve quality of life?
- How can we meet long term needs for care and resources?
- What can we do to support families and relationships?
- How can we address issues associated with aging and increased health care problems

# How can we respond to future needs of the TBI population?

- Address issues of aging survivors and aging support systems
- Develop more effective community-based options
- Develop system responses to TBI issues associated with long term survivorship
- Study long term outcomes to identify services needed as the survivorship duration increases

# Brain Injury: Ten Years Later

*What are the larger issues that confront the individual & rehabilitationists?*

- Chronic physical problems: mobility; general health; specific deficit related issues
- Complications related to burden of aging for the individual with TBI
- Social role changes
- Emotional and psychological issues
- Community access and availability of services

# Neurologic Rehabilitation Institute at Brookhaven Hospital

**888-298-HOPE**

**traumaticbraininjury.net**

*Neurologic Rehabilitation Institute of Ontario*

**www.nrrio.com**