TEN YEARS LATER:
Living in the Community with a Severe Brain Injury

presented by

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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?

- 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

Source: NRIO Outcome Study, 1993-2002
What are the community living problems that are seen in individuals with complex care needs?

- 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

Source: NRIO Outcome Study Reports, 1993-2002
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?

- 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

Source: NRIO Outcome Study Reports, 1993-2002
What trends are occurring in the survivor population that will continue to affect community living?

- 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)

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