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# What Can We Do About Long-Term Sequelae of Traumatic Brain Injury?

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A major issue confronting persons who have experienced traumatic brain injury (TBI), and those associated with their recovery, is preparing and crafting a life beyond the formal rehabilitation phase. Said another way, persons who have had a TBI often find themselves back in their pre-injury environment but unprepared for re-entry to their former lives. Family demands are often more challenging, work demands more difficult, the injured person's psycho-social support system permanently altered. In this article I review the literature pertinent to the functioning of persons with TBI after they have finished the acute medical and rehabilitation aspects of their care and have entered the phase of rehabilitation known as "post-acute and long-term" care.

When we talk about "recovery" from TBI, we first need to establish the severity of the injury. Fortunately, most TBIs are mild and produce few long-term negative consequences. About 75% of all brain injuries fall into this category, and the overwhelming majority of patients resume their pre-injury lifestyles (although some of them do achieve less than optimal recovery<sup>1</sup>). The smaller fraction who sustain injuries classified as severe are much less likely to be able to return to their pre-injury lifestyles; in some cases they never return to work, school, or family roles.<sup>2</sup>

We must then understand that the injured person, regardless of how severe the injury, will spend the much greater portion of his or her life outside of the medical setting. This means that once the patient is discharged from inpatient rehabilitation, health care professionals are likely to "be there" for them only at the time of an acute care event like an emergency room visit, a medication reaction, or a new injury. This does not imply any insensitivity on the part of health care professionals; it is simply the natural sequence that patients—like all of us—return to

their homes and communities to adjust to the events, both positive and negative, that shape their lives. The difference for roughly 2% of the population of North Carolina is just that *the event* is traumatic brain injury.<sup>3</sup>

Finally, we must realize that the goals and objectives of the post-acute and long-term providers of services for persons with TBI are quite different from those of medical providers who take care of patients on the "front end." For example, emergency services providers seek to establish life support, medical stability, and the beginning of treatment that will maximize the injured person's ability to return to pre-injury level of communication, mobility, and emotional health. Such acute care services are necessary prerequisites to the continuum of care that leads to rehabilitation of TBI. But the goals of the post-acute (out of hospital) health care provider are more global, often focusing on the potential of the injured person to return to work, to school, to their roles as spouse, parent, son, or daughter, and to their position in the community.<sup>4</sup> To accomplish these goals, the health care professional providing long-term services to the person with a TBI must have a clear appreciation and understanding of his or her abilities, interests, and desires *both before and after* the injury. This turns the focus of treatment away from narrow medical concerns, such as medications, appointments, and surgical procedures, toward overall lifestyle and quality of life.

## What Does the Literature Tell Us?

Looking at the medical and research literature on the long-term outcomes of persons who have experienced TBI, it does not take long to see that *medical* issues are far less prominent than *non-medical* concerns. For example, the research literature quite consistently demonstrates that social isolation is one of the most significant hurdles faced by many persons with brain injury,

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particularly those with moderate to severe injury, who often experience slow and gradual loss of interaction with family members, and their pre-injury friends and acquaintances.<sup>5</sup> As would be the case for anyone, injured or not, loss of support has a major negative impact on quality of life.

I alluded earlier to the “continuum of care” for persons with TBI. This special edition of the *Journal* emphasizes the fact that TBI care is not a simple medical problem but one with major psychosocial, vocational, and family consequences—all of which need attention. The challenges exist long after acute medical interventions are over. A recent edition of the *Journal of Head Trauma Rehabilitation*<sup>6</sup> illustrates the complex and difficult path that recovery from TBI often takes. The articles in that special issue, which focused upon long-term outcome following TBI, indicate the following:

◆ Re-hospitalization is common, occurring in about 23% of cases during the first year after injury and in 17% during the fifth year after injury. Many re-hospitalizations during the first three years are “elective” (for orthopedic and reconstructive surgery), but thereafter re-hospitalization is less likely to be elective and more likely to involve management of seizures, psychological problems, or infections.<sup>7</sup>

◆ Studies of persons with TBI demonstrate improved function after rehabilitation, but instruments currently available for documenting such change may not capture the quality of change or the specific nature of those changes.<sup>8</sup>

◆ Quality of life after TBI is influenced most by the injured person’s mental health status, then by his or her perceived physical health, employment, and leisure status.<sup>9</sup> Unfortunately, very few programs in the United States focus primarily on long-term quality of life after TBI.

◆ Neuropsychological (cognitive) recovery from TBI can take several years. This runs contrary to studies published in the 1980s and early 1990s, which suggested that cognitive improvement reaches a plateau after 12–18 months. The recent study offers more encouragement about the potential for recovery of cognitive function than was earlier perceived.<sup>10</sup>

◆ Persons who were provided a continuum of care—from acute to post-acute—generally had durable rehabilitation outcomes, maintained for several years after discharge from a formal rehabilitation program.<sup>11</sup> Perhaps the most important finding was that even persons with severe TBI continue to make functional gains several years after injury, if they are given appropriate long term care services. This finding was also reported from a study of a large group published several years ago.<sup>12</sup>

◆ The families of persons with TBI can have quite complex and demanding needs, even many years after the

injury.<sup>13</sup> They may need instrumental support (for home and life-style maintenance), emotional support, or support to maintain their own health status, which is at higher risk than in persons who do not have care-giving roles.<sup>14</sup>

## The Challenges of Life After TBI

TBI can have dramatic, usually negative, effects on vocational options, the ability to live a sustained, independent life, and overall quality of life. The kind of outcome an individual achieves is the result of a very complex interplay of pre-injury issues, such as employment and educational history, injury-related issues like severity of injury, access to a continuum of care, and post-injury issues including family and employer support, and psychological reaction to the injury.<sup>15</sup>

There is considerable discussion in the professional and lay community about how persons with TBI “age.” Does injury to the brain impose medical and psychosocial vulnerabilities in late life that are avoided by persons without TBI? The literature on this topic is very preliminary, but there are several ongoing research efforts, including those of the Long Term Care Committee of the American Congress of Rehabilitation Medicine and the TBI Model Systems.<sup>16,17</sup>

The availability of long-term TBI services in North Carolina is less than ideal. The injured person who cannot maintain an adequate quality of life at home, with or without the support of family and friends, has few programmatic options available. The most recent edition of the National Directory of Brain Injury Rehabilitation Services<sup>18</sup> lists only two providers of long-term care for persons with TBI; both are branches of Learning Services Corporation, located in the Raleigh-Durham area. There may be other service providers, for example home based care and extended outpatient services, that are unlisted, but the general consensus within the North Carolina TBI community is that there is a very short supply of long-term, quality-of-life-oriented programs in the state.

Even greater is the need for long-term, post acute services in programs with a neurobehavioral focus, and that serve the clients who are most difficult to manage (persons who are non-compliant with their treatment, at risk for substance abuse, have impulse control problems or life threatening post-traumatic depression). A private, for-profit facility (Learning Services Neuro-Behavioral Institute) recently opened in Creedmoor, NC. It is designed to address this special need. But we still need programs to serve this subgroup of the TBI population who lack the financial backing to pay for this program.

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## Summary

It is wrong to think that the needs of persons with brain injury are met or complete in the first few months—or even the first few years—after injury. Some persons with TBI may recover in the acute and out-patient care setting sufficiently to return to home, school, or job, but there is a large group who can greatly benefit from extended care. Extended care can take the form of day activity programs, or respite care for caregivers and injured persons, or supported employment, or home-based services, or long-term residential care. The Commission on Accreditation

of Rehabilitation Facilities has recently established standards of care for “assisted living” to provide guidelines for agencies providing long-term care for persons with various disabilities, including TBI.<sup>19</sup>

It is my strong opinion that private and government-based providers must work hand-in-hand to develop and maintain quality, long-term living options for persons with TBI. Such a collaboration, if sustained, would almost certainly give persons with brain injury and their families a much better chance of returning to pre-injury lifestyle or other preferred options.

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