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Long-Term Challenges

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As triumphant as the survivor, family, and neuro-rehabilitation team may be on the day of a successful discharge, it is premature to forecast continued growth or even stability at a later date. Numerous studies suggest ongoing challenges experienced by both survivors and caregivers, which can persist years after the injury, and long after rehabilitation ends, as is illustrated by the case of LV, below.

The accident struck me like a lightning bolt. A speeding motorist rear-ended my car, fracturing my skull, causing a severe brain injury. I was comatose for 35 days. I would not be returning to my previous life. My eyes crossed. I lost my sense of smell. I experienced severe coordination and balance difficulties. I had major visual challenges as well as cognitive and emotional difficulties.

Before the accident, I balanced my family (husband and two young sons) and career as a dentist successfully. I was just 49 years old, youthful and dynamic.

Post-injury, following the prolonged coma, I started the neuro-rehabilitation journey, which has been my primary job since the accident. I followed all the steps from acute to post-acute inpatient programming, shifting to daily, intensive outpatient therapies, and gradually reducing to part-time outpatient rehabilitation as my condition improved and my needs changed. It took 21 months to finally return home and become an outpatient.

I had corrective surgery to reposition both eyes for accident-induced esotropia and diplopia. Esotropia was eliminated but diplopia persists to this day. My double vision has been corrected through the use of prismatic lens eyeglasses. The improvement in my vision has also helped to increase my balance. I have been struggling to be cleared to return to driving and was recently re-authorized to drive again, eight years following my injury.

I was in a wheelchair for approximately 3 years followed by 2 years of using a walker. For the past few years, I have been using a cane to help me ambulate due to residual balance difficulties. I have made enormous gains in all areas, including my thinking skills, especially memory, emotional status, and in the use of compensatory strategies to work around my weaknesses.

Identified long-term challenges include a high incidence of perceived needs and ongoing barriers (Corrigan et al., 2004; Powell et al., 2001); frequent re-hospitalizations (Cifu et al., 1999; Marwitz et al., 2001), persistent cognitive and emotional difficulties (Pagulayan et al., 2006), and social isolation (Dikmen et al., 1993; Oddy et al., 1985; Weddell et al., 1980).

In addition to being persistent, many of these changes/challenges worsen with age (Brooks et al., 1987; Felicetti et al., 2005) and the development of a variety of health-related problems as brain injury survivors age has been noted (Hibbard et al. 1998; Felicetti et al., 2005). Correlations have been found between traumatic brain injury (TBI) and early cognitive decline (Houx et al., 1991), and Alzheimer's disease (Starkstein & Jorge, 2005).

The long-term effects of brain injury are not only on survivors. Caregivers report high levels of stress/burden (Verhaeghe et al., 2005), and have been shown to have a high incidence of accidents/injuries themselves, particularly those experiencing greater levels of stress (Hartke et al., 2006).

In his study of community integration following TBI, Corrigan (1994) noted that an ideal outcome occurs when the survivor is satisfied with his/her life, is contributing more to society's shared efforts than he/she is dependent on them, and is able to sustain a state of physical and mental health that also contributes to the health of others in his/her life. Thus, success is a multifaceted concept, and must be measured not only by clients having met identified discharge goals, but by their being able to participate actively in home, community, work, and/or school settings; their emotional and physical health; the quality of their relationships; and the stability of these activities, states and relationships over time. Following this tripartite model, Sherwin et al. (2006) proposed a minimal data set by which to standardize the measurement of community integration outcomes following TBI, to facilitate program comparison and evaluation.

Given the above considerations, it is clear that responsibilities of the neuro-rehabilitation team do not end on the day of discharge from rehabilitation. Our goal must be not only to achieve successful short-term outcomes of our interventions, but to have these outcomes extend beyond the rehabilitation phase, so that the survivor and family are able to maintain their achievements and successes, and continue to grow and thrive throughout the remainder of their lives. How do we achieve this "extended" level of support?

Preparing for Discharge

It is commonly said among rehabilitationists that discharge planning begins upon the day of admission. While some survivors and families may be taken aback by discussion of discharge planning so soon upon entering the rehabilitation program, this focus is critical to facilitate a smooth transition from one phase of recovery and rehabilitation to the next, maximizing the potential for success and preventing setbacks. It is essential for the neuro-rehabilation team to project survivor/family needs beyond their current status, and begin to lay the groundwork for the next step(s). For example, the acute rehabilitation team should work with the client/family to identify post-acute-rehabilitation needs (e.g., after acute-inpatient care and home or outpatient therapies), and locate appropriate programs/services from which the family can then visit and choose. The outpatient team must identify community/work re-integration options (e.g., competitive employment, vocational training, volunteerism), and begin working toward those goals while the client is still in rehabilitation. Post-discharge medical and psychosocial supports must be identified and discussed with the survivor/family, along with education regarding the importance of developing community-based support structures/systems, in order to maintain health and wellness once formal rehabilitation services have ended.

Specific Post-Discharge Challenges

Return to Work

As acquired brain injuries (ABIs) occur to individuals from every possible profession, the neuro-rehabilitation team has the challenge of assisting clients in returning to a wide variety of careers. These professions include various fields in medicine, law, business, and accounting as well as police work, maintenance, office work, and housekeeping. Clients who were unemployed pre-injury pose a different type of challenge, many having pre-injury vocational issues which need to be addressed along with the post-injury challenges.

There are six primary challenges noted clinically that hinder return to work post-ABI: lack of readiness, suitability, support, stability, insight, and incentives. Lack of readiness refers to inappropriate timing. Survivors who return to work prematurely are at high risk for failure. Lack of suitability refers to the fact that a survivor’s pre-injury work may no longer match his or her post-injury level of functioning. Clinical examples include a cab driver that became legally blind, a construction worker with balance problems, a teacher with aphasia who no longer can communicate functionally, or an accountant who struggles to perform basic calculations. Loss of work identity presents a radical challenge to an individual’s self-definition. Once the survivor is emotionally ready to accept a new role, he or she may choose vocational retraining, meaningful volunteer work, as in the continued case of LV below, or a more active role at home.

As a result of some of my residual difficulties, a return to my profession wasn’t possible. Since I loved my profession but could no longer practice, I worked hard to obtain an appointment as a clinical assistant professor at a school of dental medicine. I have spent the last 6 years as a volunteer faculty member at the dental school, where I’ve instructed students in correct radiography techniques and interpretation.

Lack of support refers to an employer’s creation of barriers to a survivor’s re-integration to work. Clinical experience has shown that many supervisors have difficulty accepting an employee’s post-injury changes, such as reduced speed on tasks, the need for compensatory strategies to aid memory and learning, behavioral differences, reduced attention to grooming or hygiene, and difficulty understanding humor. These variations may be quite subtle and even within normal limits but are less acceptable when compared to pre-injury performance standards. Despite protection provided by the Americans with Disabilities Act (ADA) of 1990, an unsupportive employer can sabotage a survivor's successful reentry. Providing education and counsel to supervisors can be very helpful in developing empathy and understanding. Lack of emotional or medical stability will prevent a successful return to work for numerous reasons. Challenges with alcohol or substance abuse have also been linked to failure in community reintegration (Dell Orto & Power, 2000). Lack of insight challenges were reviewed in Chapter 14. Survivors with awareness deficits believe they can return to work prior to their actual readiness, and often return pre-maturely, resulting in failure. There can be various disincentives to return to work which surface during the rehabilitation period. These include financial (e.g., potential to jeopardize social security/disability benefits), legal (e.g., pending lawsuit), and emotional/psychosocial disincentives (e.g., adoption of the "sick" role).

In order to optimize a survivor's reintegration to work, it is strongly recommended that the appropriate steps be followed (Malec & Moessner, 2006). Firstly, it is important to integrate vocational rehabilitation goals with general interdisciplinary therapy goals while the survivor is in the neuro-rehabilitation program. Simulating work responsibilities is critical in assessing survivor readiness. Once the client is doing consistently well in the neuro-rehabilitation program and is successful on all simulated tasks or work trials, the time is appropriate to coordinate with the individual's work supervisor to begin discussion regarding a gradual return to work and any needed reasonable accommodations. The work supervisor will need input on the survivor's current strengths and weaknesses and the most effective ways to best facilitate his or her return to work.

In cases where survivors are no longer well suited for their former careers, various options are possible. They may choose to retrain through state or privately funded vocational agencies/programs for individuals with disabilities so that they can begin a new career based on their current strengths. They may be able to find competitive or volunteer work in their field in a modified position. Survivors who were physical laborers prior to their injuries may choose to become caretakers for their children or homemakers for their families, especially in cases where they are not able to return to physical work and are not interested in returning to school or pursuing a different career. Additionally, given the wide range of volunteer opportunities in major hospitals, nursing homes, public schools, university settings and libraries, many clients are able to find a suitable position that can be both fulfilling and flexible, in terms of hours/days.

In cases where survivors are not appropriately supported by their employers in their efforts to return to work, it is critical that support be provided by either a job coach (funded by state, county, or paid for privately) or by a primary therapist/ counselor assisting the transition to work by maintaining regular contact and exchange of information with the employer. If the survivor is able to perform his/her essential job functions and the employer is not willing to provide reasonable accommodations, legal action may be necessary.

In terms of medical stability challenges in returning to work, it is critical that survivors have ongoing medical follow-up, especially in cases of seizure disorders or pain syndromes. The degree of control that a survivor has on medical challenges will greatly influence his/her attempts to successfully reintegrate to work. Continued counseling during the reintegration process can significantly assist the survivor in maintaining emotional stability and coping with difficulties that arise. Follow-up counseling sessions can also assist survivors in improving their awareness level as well as coping with mood challenges that may emerge once insight increases. Counseling/psychotherapy can also help survivors overcome various disincentive barriers.

School Re-Integration

A comprehensive review of challenges and strategies to facilitate school re-integration following brain injury is beyond the scope of this chapter. While some school districts are very supportive and welcoming of recommendations for students reintegrating back to school, others have great difficulty adjusting their policies or standard procedures in order to provide the necessary accommodations. Some survivors are able to easily return to school with accommodations and resource room help. Others may need a more specialized school setting that offers more individualized attention and flexibility. Due to severe emotional or behavioral difficulties, certain students may need one to one tutoring in place of a classroom setting until they are ready for, or can tolerate, group interaction. The neuro-rehabilitation team must partner with the school system (which becomes part of the care team for the survivor), serving as advocates, educators, and advisors, in order to ensure the student receives all of the supports that he/she needs in order to achieve a successful return. Taking advantage of supports available through county/state agencies or advocacy groups can also be of assistance.

Social/Leisure Involvement

Persistent difficulties in areas such as executive function, communication, vision, and balance will pose particular challenges with regard to maintaining or redeveloping an active social life following brain injury. Barriers toward social re-integration typically include a lack of transportation, withdrawal of pre-injury friends, and financial limitations. Lower-cost, accessible transportation options (e.g., county/state para-transit services for persons with disabilities) for those survivors unable to return to driving, afford taxis/car service, or manage the complexities of using the public transportation services must be explored and facilitated by the rehabilitation team prior to discharge, so they are available when the survivor will need them. Information about community-based advocacy and support services (e.g., local, regional advocacy associations, support groups) should be given, as well as information/support available in the home (e.g., internet-based support groups, websites, and long-term home and community-based support services).

The neuro-rehabilitation program itself can and should develop a mechanism for providing post-discharge support services, which can extend the neuro-rehabilitation continuum of care, offered at low to no cost to survivors and families following discharge from formal rehabilitation. These can include alumni and caregiver support groups, which can provide an opportunity for continued education, networking and validation of feelings and experiences. Other post-discharge support services can include educational (e.g., wellness) programs, exercise programs, weekend activities, volunteer opportunities, and peer mentoring. Telephone follow-ups can help to identify barriers or challenges, allowing proactive interventions to be made in order to avoid crises. Bell et al. (2005) have demonstrated the effectiveness of such telephone interventions in producing positive outcomes. These types of post-discharge services can offer a sense of security, ongoing support, and connectedness/community that is often lacking in the post-injury lives of survivors and families.

For many, the onset or experience of an acquired brain injury is a life-changing event, with lifelong consequences, affecting not only the injured person, but also their families and communities. The period of rehabilitation following such an event becomes a critical, though not exclusive, component of the rebuilding of the life that has been altered, and the healing that must take place, as is demonstrated by the continued story of LV.

> *I believe that my excellent recovery so far has been due to the combination of the intensive, integrative therapies I received as well as my strong determination. My gains would have been impossible without either component.*
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> *What lies ahead? I hope that I can continue to establish new pathways in the unused portions of my brain to help further boost my walking, talking, vision, fine and gross motor skills, as well as balance. These days my cognitive and emotional/social statuses are at pretty good levels.*
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> *My greatest challenge over the past 8 years has been to stop bemoaning my losses and get on with my life as fully as possible. I know I will always bear some scars from the brain injury, but I am hopeful about the future. I expect to continue to get stronger and better able to function. I hope to continue to be an example of fortitude and perseverance in the face of the unexpected. I've learned that you always have to be prepared because you never know how life's rudders will twist and turn your pathways.*

The neuro-rehabilitation team has an enormous responsibility; not only to ensure the excellence and effectiveness of formal rehabilitation services provided, but the coordination of such services to meet the holistic needs of the survivor and family, and the extension of services beyond the period of formal rehabilitation, to facilitate the maintenance of function and quality of life, and continued health of those whom we serve.

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