

Life Care Planning for the Adult with Traumatic Brain Injury

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Traumatic brain injury (TBI) is not a singular impairment. It originates from many different sources and represents diverse impairments that can dynamically affect almost any aspect of daily life. Hence, comprehensive, contextual and holistic perspectives are required to develop life care plans. As aptly noted 80 years ago, "it is not only the kind of injury that matters, but the kind of head" (Symonds, 1937). Multiple factors create the unique multivariate signature of each TBI. This includes the nature of injury onset; the intensity, inflection, nature, and foci of cerebral insult(s); comorbid injuries; the focus, time and quality of initial care; appropriateness of subsequent treatment; premorbid status; age at onset; history of neurological insult; and other issues. Attempting to ascribe TBI outcome to any singular factor is likely to be erroneous. For example, the Glasgow Coma Scale is often used to estimate initial injury severity, but singularly has limited prognostic value.

Similarly, identification of a TBI in an index event (the injury or medical event that originated subsequent disability) alone is often insufficient to ascribe causation. Additional information is required to determine if the TBI is the predominant factor of subsequent sequelae, a concurrent factor, a secondary issue, or inconsequential. Challenges to causation may be more frequently noted in cases of concussion or mild TBI if less direct signs of neurologic impairment are evident, or if there are competing hypotheses of attribution. Deliberations regarding causation are typically the province of treating and evaluating professionals, but sometimes also the life care planner if so qualified. Ultimately, each life care plan relies on the quality of all available case data, treatment, diagnoses, course and methodology to establish credible foundations. The remainder of this article focuses on cases that involve TBI.

Traumatic Brain Injury as a Dynamic Process

The longitudinal course of a TBI is as important as its initial effects. Not all impairments may be evident at the time of onset and secondary complications can surface. Recent literature has identified TBI as a chronic, life-long disease process (Masel & DeWitt, 2010). Traumatic brain injury may affect pre-existing conditions and alter their previous management protocols. There may be comorbid injuries that contribute their unique impairments, especially when this

involves significant orthopedic, spinal cord, burn or other large system injuries. During the process of triage, such injuries may take priority over TBI, or mask neurological, cognitive and behavioral TBI sequelae until their relative stabilization.

Personological, environmental and contextual factors require equal consideration. They play important roles regarding return to premorbid routines and responsibilities. Changes in cognitive, emotional, and behavioral profiles often have more dynamic and pervasive effects on long-term outcomes than initial medical and physical impairments. For example, increased impulsivity, diminished self-awareness and altered moods can affect a broad spectrum of social relationships from intimacy, to community acceptance, to work. Behavioral problems are a primary reason that individuals are rejected from or prematurely discharged from treatment, or alienated from family and friends. Personal history also interacts with presenting impairments. For example, selected memory or problem-solving impairments may adversely affect someone just entering the job market where new learning is essential. Conversely, a person returning to a long-standing and well-learned position may be less affected by such challenges, though other issues may cloud capacity. Social and cultural values, lifestyles and how the individual is regarded by others require similar consideration. What may be acceptable in one community or social support network may be repulsive in another.

Life Care Planning Methodology

The conceptual basis of life care planning addresses many complex issues surrounding TBI. Life care plans characteristically reflect the structure, context and qualitative relationships of the "whole" individual and not just immediate impairments. They document services and supports required to facilitate lost or altered premorbid capacities, preferably within personally relevant daily activity patterns and environments. Sometimes, required services and supports are not locally available, substantial deficits may require specialized services, social support networks may deteriorate, or changes occur relative to personal competency. Still, life care plans emphasize prospective services that support functional capacities and life quality.

Qualified life care planners are required to follow a

consistent methodological process to establish reliable and valid findings. This approach has been well reviewed in the literature (Weed & Berens, 2012) and is briefly noted here. Salient steps include:

- (a) Comprehensive review of all available records and supportive documentation.
- (b) Interview of the injured party at his/her place of residence when possible, as well as family members or other key collaterals who know the person both before and since injury onset
- (c) Direct consultation with treating and/or evaluating professionals to establish foundations for requisite needs and services, in addition to or in support of any identified in the records review and interviewer information
- (d) Reference to clinical practice guidelines and relevant research literature, as needed, to further establish recommendations and plan foundations
- (e) Identification of personally appropriate, clinically relevant, and accessible services and supports to specifically meet identified recommendations
- (f) Documentation of charges associated with each identified recommendation specific to location and service
- (g) Practicality in the recommendations relative to presenting needs, individual capacities, available resources and lifestyle

Special Considerations When Evaluating an Adult with TBI

Developmental processes and history often distinguish life care plans for children and adults. Children are in developmental accession, which can be uniquely and longitudinally affected by TBI. Their social support networks and skills repertoires are evolving. Adults have typically reached their medical and neurological asymptote, or are in age-related regression. Adults also have more diverse life experiences that may affect analysis of capacities, presenting challenges and topical treatment approaches.

Premorbid History

Clarifying premorbid capacities and limitations is important. Here the goal is amelioration of index event related disability and handicap. Review of pre-morbid records, interviews with the injured party and other sources can substantiate a wide array of past personal capacities and challenges and their current relevance. Understanding the context of previous cognitive, emotional and physical capacities and deficits is required to effectively outline which lifetime care needs are related to the TBI.

Current Treatment

Records reflecting current treatment require similar consideration. Not all current medical treatment, medications or other services are necessarily related to the

index event; e.g., annual health maintenance and premorbid treatment regimens for medical conditions such as hypertension, diabetes, asthma, pain, or other disorders not associated with TBI.

However, changes in personal capacities attributed to the TBI may affect associated treatment compliance or exacerbate premorbid conditions. Hence, a person who now has problems with organization or memory may no longer be able to independently manage medications, diet, prosthetic care or other protocols. Comprehension problems may require longer medical appointments and participation by a second party. Disinhibition may rekindle intervention for previously well controlled episodes of substance abuse, legal or mental health issues. Life care plans may include additional resources in order to re-establish premorbid homeostasis.

Medical Considerations Following TBI

Survivors of TBI can face diverse medical sequelae. These may be transient or lifelong problems, which can impact activities of daily living (ADL), social interaction and employability. Physiological sequelae may present themselves immediately after trauma or years later (Brown, Hawker, Beaton, & Colantonio, 2011). Some of the more common problems include balance, ataxia, apraxia, fatigue, thermoregulation, endocrine disorders, respiration, incontinency, appetite, dysphagia, paresis/paralysis, seizures, insomnia, headache, pain, sexual dysfunction, spasticity and changes in any of the senses.

Treatments can include medication, surgery, nerve blocks, physical therapy, occupational therapy, speech therapy, recreational therapy, hippotherapy, music therapy, aquatherapy and other modalities (Archer, 2012; Nudo & Dancause, 2013). Modalities are often combined, hence, problems involving contractures and spasticity may require splinting, casting, nerve blocks and/or surgical intervention (Bell & DiTommaso, 2016). Pain management often requires a combination of pharmacological intervention, skilled therapeutic modalities and counseling (Tyrer & Lievesley, 2003). Durable equipment, such as canes, crutches, and wheelchairs may be necessary and will require fitting, training, periodic maintenance, replacement and upgrading over one's lifetime.

Aging

A number of problems encountered during the aging process are specific to or exacerbated by TBI (Konrad et al., 2011; Sendroy-Terrill, Whiteneck, & Brooks, 2010). People with TBI may be at increased risk of Alzheimer's disease, non-Alzheimer's dementia and brain atrophy (Dams-O'Connor, Guetta, Hahn-Ketter, & Fedor, 2016; Nordström, Michaëlsson, Gustafson, & Nordström, 2014). Cognitive and sensory declines as well as deterioration of balance/ambulation seen with normal aging can be accelerated and magnified following TBI. People with TBI

are at greater risk for age-onset depression and suicide. They are more likely to require in-home care, home modifications, and/or admission to assistive living or skilled care facilities, and at an earlier age. Lifetime monitoring may be required to adjust care and living situations according to progressive deterioration.

TBI and Life Expectancy

People with TBI may have reduced life expectancies. As a heterogeneous population, multiple factors impact these findings. Most life expectancy studies have focused on moderate to severe TBI. Here, variables influencing the reduction include age at injury, gender, injury severity, disability level at rehabilitation discharge, premorbid employment, drug use and marital status, and quality of medical insurance (Brooks, Shavelle, Strauss, Hammond, & Harrison-Felix, 2013; Harrison-Felix et al., 2012a; Harrison-Felix et al., 2012b; Selassie, Cao, Church, Saunders, & Krause, 2014). Published life expectancy tables, derived from large cohorts of people with moderate and severe TBI who survived at least a year distinguish life expectancy by those who can walk well, have difficulty walking, cannot walk but can feed themselves, and can neither walk nor feed themselves (Brooks, 2015). Individuals with mild TBI who survive more than six months have no reduction in long-term survival compared to unimpaired populations (Brown et al., 2004; Brown, Leibson, & Malec, 2005).

Individual estimates of life expectancy should begin with reference to high quality published data. Once a starting point is identified, clinicians may then use their professional judgment to adjust life expectancy due to other individual patient characteristics (Brooks et al., 2013).

Psychological/Behavioral Symptoms

Psychological/psychiatric/behavioral deterioration occurs for many different reasons following a TBI and creates barriers to socialization, intimacy, education, employment and community tenure. Some of the most prominent challenges include frontal lobe apathy, emotional lability, anger/frustration, depression, anxiety, disinhibition, hyperactivity, dysfunctional sexual behavior, hoarding and immaturity (McAllister, 2008; State of Colorado Dept. Labor and Employment, 2012). Common treatment modalities include counseling, behavior analysis, positive behavioral supports, medications, structured environments and mentoring.

Behavioral changes may occur due to direct neuropathology of cerebral areas, disruption of neurotransmitter production/absorption, or damaged neural pathways. The paradoxical effects of medications prescribed to address such imbalances can produce provocative side effects (Levine, 2013). Neuromedical conditions including seizures, pain, insomnia and vertigo may contribute to behavioral aberrations. Alterations in perceptual functioning

directly affects how a person perceives and understands his or her world, thereby affecting behavior. For example, a person with visual-spatial deficits who is unaware when they invade someone's personal space may be labeled socially aggressive. Conversely, acute awareness of one's lost capacity can procreate anger, resentment, anxiety, depression and other neurobehavioral challenges. Without careful assessment, the actual variables influencing observed behavior can easily be masked by other's judgment of the person's "intent." This can affect proper treatment recommendations, and produce iatrogenic effects.

Cognitive Capacity

Common cognitive impairments include disorientation, distractibility, confabulation, impairments in short and/or long term memory, abstract thought and reasoning, sequencing, initiation and perservation (Neumann & Lequerica, 2015; State of Colorado Dept. Labor and Employment, 2012). These impairments affect everyday activities such as ADL's, education, work, community integration and financial management.

Each of the primary cognitive domains is multifaceted in organization, operation and effects on performance. Most human performance is not the product of any one specific cognitive ability, but the integration of many different components (Lezak, Howieson, & Loring, 2012). Aberration of any individual component can alter performance. Assessing individual cognitive domains in isolation, without reference to other personal capacities, or without regard to personal environments and situations may yield inaccurate assessments. Hence, memory performance may be further affected by other cognitive capacities involving attention/concentration, inhibition/disinhibition, fatigability, comprehension, organization, planning, problem solving, adaptability, multi-tasking, self-monitoring, etc. These later abilities, often labeled as executive functions, relate to higher level cognitive skills used to navigate daily life demands and can reflect a person's relative independence and resilience. In many situations, difficulties using and managing information is more debilitating than any likelihood of decreased intelligence following TBI.

The diversity of cognitive challenges results in a multitude of treatment and support approaches (Koehler et al., 2013). Assessment and treatment sessions may be conducted in inpatient or outpatient centers by skilled therapists. Cognitive prostheses consisting of schedules, calendars, tasks-lists, notebooks, and apps are often suggested (Chu, Brown, Harniss, Kautz, & Johnson, 2014; Cooper et al., 2013), but careful selection is required and there may still be no guarantee of effectiveness. People may forget to enter pertinent information, not access the prosthesis in a timely manner, forget about it, or find it either irrelevant or too complicated to use. Training the individual is necessary to assure regular use, and continuing in-situ

supports may still be required. Pharmacological interventions may also help mitigate cognitive problems (Dougall, Poole, & Agrawal, 2015).

Context and Structure

Changes in functional capacities due to above noted challenges can compromise the context and structure, essentially the fabric of the injured person's life. This, in turn, can compromise functional capacities, which can further affect context and structure, etc. Sometimes, noted effects are manageable with appropriate supports; for example, job coaching to sustain employment, modification of daily routines, or mentors to bridge social deficits. These approaches may help resolve specific functional deficits and help the person remain in familiar settings where other naturally occurring supports and associated adjunctive benefits promote preserved skills and facilitate overall life quality.

In other cases, greater incapacity can preclude continued participation, with potentially cascading effects. For example, in addition to losing vital income, job loss also removes the person from a contextually rich environment that supports a wide range of roles, skills and productive activity patterns; access to diverse social networks and reciprocal relationships; mobility; and personal and social validation. This may promulgate other problems related to mood/anxiety, health, participation and behavioral dysfunction.

Similar broad based dysfunction/incapacity may occur with transition to new environments, loss of key friends or family, or other keystones of a person's life. Successfully addressing associated issues may require holistic and contextual approaches as compared to symptomatic treatment. For example, here, individual psychotherapy and medication may be less effective in addressing depression than helping the person establish meaningful activities of personal interest and social reciprocity. The life care planning and brain injury literature supports the importance of productive and meaningful activity in order to promote physical and emotional well-being, community integration, active engagement and life quality (Berens, 2008; Jacobs, 1997; Reid & Riddick-Grisham, 2015; Weed, 1991).

Treatment Modalities

Required services and supports following TBI may transcend commonly considered treatment regimens. Traditional diagnostic and treatment services remain crucial, but may be insufficient, especially when the person with TBI is unable to transfer recommendations to his or her daily life.

In-home 1:1 or close supervision services are sometimes considered for people with significant medical challenges, who require extensive assistance with ADL's, who wander, have poor judgment, or exhibit significant behavior dysfunction. These "sentry" services, typically provided by

direct care level caregivers, often focus on keeping people safe and out of harm's way. The protective nature of such services, in the absence of other contextual considerations, can sometimes evoke frustration for more active and mobile individuals who consider it "baby-sitting." Similar effects can occur with placement in traditional day programs that may offer greater respite for caregivers than engagement for participants.

Embedded supports such as mentors, life skills coaches and job coaches work in people's natural environments on a real-time basis to engender productive outcomes. This can include assuring treatment compliance, organizing / managing households, shopping, planning and participating in community activities, working in job or volunteer positions, problem-solving unexpected circumstances, and other issues. Sometimes, these supports remain for a limited duration until situational mastery is achieved. Other times, continuing supports may be required to sustain productive capacity and safety.

Prosthetic (structured) environments provide supportive and contextually relevant milieus to facilitate personal competencies. They may include community-based "Clubhouse" programs (Jacobs, 1997), day or residential programs for individuals with greater challenges. Well-staffed residential programs may be considered following initial hospitalization or around other clinical epochs/transitions. Their 24/7 operation allows comprehensive evaluations of functional skills, data-based optimization of medication protocols, competency-based training of durable equipment and cognitive prostheses, and pragmatic transition of integrated service plans to support sustainable community integration (Benge, Caroselli, Reed, & Zgaljardic, 2010). Again, careful assessment is required to determine the relevancy and proper fit of any considered services included in the life care plan.

Productive Activity Patterns and Vocational Services

Well-founded recommendations for productive activity, including vocational or avocational activity, is a well-established tenant in life care plan development. Rehabilitation outcomes research typically focuses on work or vocational activity as the "penultimate" outcome for individuals with a disability. Individuals capable of compensated employment may selectively benefit from job coaching, structured or supported employment, vocational rehabilitation counseling, training programs, rehabilitation technology and/or specialized equipment, according to personal needs and abilities (Weed & Berens, 2013).

For individuals with TBI who are not able to competitively work, participating in personally relevant and socially productive avocational activities may help establish a sense of purpose, enhance life quality and facilitate membership in a larger community (Berens, 2008). The venues and services required to facilitate such participation,

however, are likely to differ from customary vocational rehabilitation services.

Summary

Traumatic brain injury onset may initially invoke medical treatment, but for many, needs and services quickly transcend to other aspects of the injured person's life and the lives around him or her. The dynamic and interactive relationships involved in life following TBI onset require careful analysis and contextually based treatment, often on a lifetime basis. Carefully constructed life care plans by qualified professionals can provide cogent direction to facilitate functional capacity and life quality.

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