



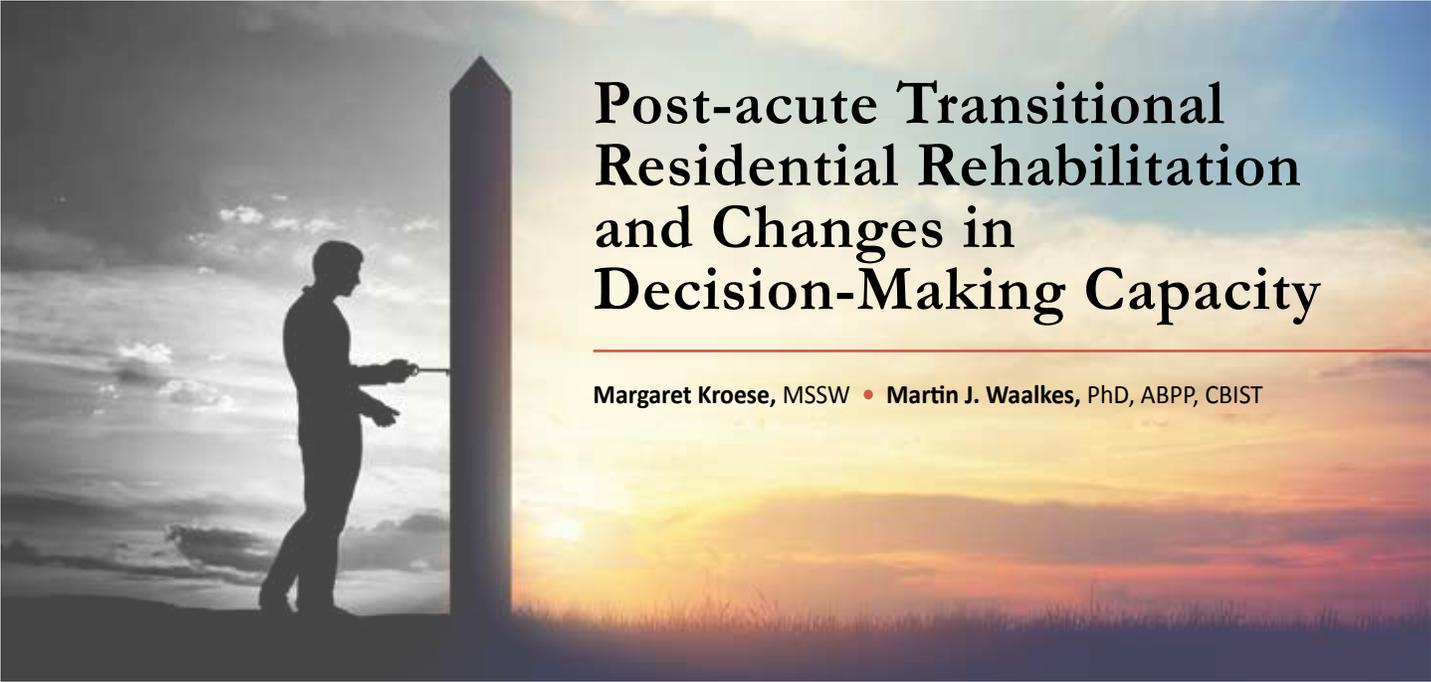
Major Issues in Post-acute TBI REHABILITATION

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FEATURE:

“POST-ACUTE TRANSITIONAL
RESIDENTIAL REHABILITATION AND
CHANGES IN DECISION-MAKING CAPACITY”

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Post-acute Transitional Residential Rehabilitation and Changes in Decision-Making Capacity

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Post-acute transitional residential rehabilitation (TRR) is an intensive, post-hospitalization rehabilitation service model that focuses on functional recovery and disability mitigation. TRR programs provide highly integrated therapy interventions in order to maximize recovery and actively build the supports needed in the home community upon discharge. The goal of TRR is to restore a person to their most independent level of functioning.

By necessity, TRR is both intense in duration and activity. Post-acute programs provide formal treatment for up to six hours per day, at least five days per week. Additionally, Rehabilitation Aides reinforce the treatment goals during morning and evening routines, as well as throughout all other activities of daily living. Treatment length varies based on the person's needs, but typically is between 60 – 90 days. While not hospital based, TRR is experienced as an inpatient program, meaning the participant typically lives within the treatment program for the duration of care.

The treatment environment and distinct population characteristics found in the post-acute brain injury rehabilitation setting present unique ethical challenges relevant to patient decision-making capacity. Sustaining a brain injury results in readily apparent changes like physical and language changes, as well as less obvious changes like slowed thought, limited judgment or insight, and impaired memory. Cognitive consequences of the injury may affect a person's ability to make informed decisions regarding medical treatment and lifestyle choices.

In general, patients seeking medical care need the ability to understand information relevant to the medical decisions being asked of them, and to appreciate the consequences of any decision, or lack of decision, to be truly informed. Patients without this ability need a formal or informal decision maker to assist them. In post-acute brain injury rehabilitation, persons being served may move from needing assistance to having independent decision-making capacity as they progress. Professionals in these programs must recognize, support, and respond to changes in capacity over the course of a treatment program.

Early in recovery and during the adjustment to the profound changes of a severe brain injury, decision-making capacity is often absent.

Concerns of initiating treatment and weighing the likelihood of benefiting from intervention are protected by proxy decision makers with little contribution by the patient in a minimally conscious or vegetative state. This condition alone, with the uncertainties of prognosis, provokes many questions of informed consent and rights to treatment (Fins, 2015). While less grave than life and death, serious questions of quality of life and the expression of individual preferences remain. As patients show signs of awareness and can communicate their values and desires, decision makers have an obligation to reflect these wishes in the decision-making process. Many people arrive at the post-acute level of care without the ability to determine their own course of treatment. Medical decision-making capacity that was significantly impaired in patients with moderate to severe TBI at the end of their acute care hospitalization can show substantial improvement and partial recovery of the abilities over a 6-month period (Marson, Dreer, Krzywanski, Huthwaite, DeVivo, & Novack, 2005). The changing level of a patient's capacity observed as the injury and related symptoms resolve is a unique factor found in brain injury rehabilitation. A person's decisional capacity is a clinical determination by a qualified medical professional, typically a psychologist or physician with background and training in this area of assessment. While considering the person's capacity, the psychologist or physician must consider how the current medical treatment, cognitive status, and emotional, social, and contextual situation contribute to the current presentation (Hanson, Kerkhoff, & Bush, 2005). The Aide to Capacity Evaluation (ACE) is a frequently used structured interview assessment that can guide a thoughtful assessment of the domains of a capacity determination (University of Toronto - Joint Centre for Bioethics, 2003). A capacity assessment should determine the presence of the following: (1) the ability to understand the information relevant to the choice; (2) the ability to reason or rationally evaluate the choice; (3) the ability to appreciate the significance of the choice; and (4) the ability to communicate and maintain a choice (Wassenaar, 2013).

The ability to understand the relevant information is a basic element in demonstrating capacity. Cognitive deficits in comprehension, memory, or attention, which are common in brain injury, may limit the ability to truly understand the situation and choices available.

Anosognosia (a lack of awareness of the injury or the resulting deficits) can influence the ability to appreciate the nature of the injury or the challenges it presents.

The ability to reason refers to maintaining a decision-making process whereby information is weighed and compared in coming to a decision. Common symptoms of brain injury include impulsivity, irritability, memory problems, impaired reasoning, and problem solving. These and other cognitive-behavioral impairments influence decision-making quality.

The ability to appreciate the significance of the choice relates to the ability to apply the consequences of the choice to one's own life considering and integrating values and preferences. This is demonstrated by showing an understanding of the possible outcomes and implications of choices on the individual's life relative to endorsed values. This type of reflective capacity requires perspective-taking and is often limited by brain injury. Communicating a decision requires being able to express your ideas and desires to another person. Survivors of brain injury may have difficulty expressing choice verbally due to muscle weakness or other physical consequences of brain injury. However, they may still express intact capacity of their choice by other means of communication, such as technological solutions. People who experience expressive aphasia (loss of the ability to formulate language) may be sufficiently limited in their ability to communicate choices as to require decision-making support simply to express their wishes. In some cases, variable awareness and fluctuating investment creates an instability of decision expression, requiring support simply to establish necessary consistency needed for treatment.

Adding complexity to the post-acute setting, a person being served can maintain capacity in some areas of decision-making while not being considered to have capacity to make other decisions, and this can fluctuate from day-to-day (Wassenaar, 2013). Factors such as medications, external stresses, and mood or thought disorders can influence understanding, appreciation, and a rational decision-making process.

Decision-making capacity is expected to change during early treatment for brain injury. To address this, most post-acute programs incorporate structured assessments, neuropsychological testing, behavioral observations, and patient interviews in an ongoing treatment model. Multiple assessments over time indicate the change in capacity, and increases or reductions in need for assistance with decision-making.

Treating patients with changing levels of capacity poses several ethical and programmatic challenges for TRR programs. In the acute phase of brain injury rehabilitation, it is common for a family member to serve as a proxy and make medical decisions for a loved one. Typically, this is done on an informal basis, without a legal determination of guardianship, as the person is easily presumed impaired, yet generally expected to regain capacity as they progress. By the time the individual is entering TRR, substantial medical improvement has been made allowing transition out of the acute hospital setting. However, individuals admitted to TRR may not have made enough gains in the cognitive and reasoning abilities to reassert independent decision making for medical and lifestyle decisions, making the decisional capacity question more nuanced. Often, treatment is provided with a degree of suspension of informed consent in a parental or educational effort under the presumption that a person who may be superficially refusing services may better appreciate their circumstances if they can

be first supported sufficiently to recover some of their decisional capacity through rehabilitation (Caplan, Callahan, & Haas, 1987). Ironically, increasing levels of decision-making in the recovering person can create difficulty for families. While welcoming progress in the core skills supporting decision making, families may be hesitant to relinquish their role in making decisions. This dynamic can lead to conflicts between the rights of the person being served and the desires of family who may have invested immense amounts of time facilitating care during the early recovery stage. Not only does this create potential for family conflict, it also puts the rest of the treatment team in a difficult situation. While the team must be accountable to the person being served, ongoing family support is a key factor in successful long-term outcomes in brain injury rehabilitation, and alienation of the family support is unlikely in the best interest of the injured person (Vangel, Rapport, Hanks, & Black, 2005). Ideally, these conflicts can be avoided by offering proactive family education as well as family support groups throughout the healing process. Ultimately, the treatment team is responsible to the patient's best interests and legal rights, regardless of the family's concerns and desires.

It is common to find a patient arriving from acute rehab exhibiting confusion, agitation, inconsistent orientation, and memory impairment. By discharge, many of these features will have resolved or be substantially reduced. With this progress, gains are observed in resulting decisional capacity. Along the way, the recovering person should reassume a decision-making self-leadership role, as they are able. A typical treatment team in TRR includes many treating professionals including a physiatrist, psychologist, physical therapist, occupational therapist, speech language pathologist, social worker, rehabilitation aides, and other disciplines as required. Each team member must adjust their treatment in order to actively transition the decision-making authority to the person being served as he or she demonstrates readiness. Excellent team communication is key to making this transition one that is coordinated and successful.

Not everyone will progress enough during rehabilitation to be independent in decision-making and may, instead, require formal temporary or permanent guardianship. Typically, this path will not be pursued early in rehabilitation in the hopes that gains will be made, although determination at the early stage is more straightforward. At some point, the treatment team will need a formal decision maker with full legal authority who can help establish the future plans of the individual. For those who show impulsivity or unawareness of their deficits, the issue of formal guardianship is often addressed earlier in rehabilitation in order to assist in participation and designating long-term support options. Treatment refusal can be a very good reason to seek formal guardianship for a person who does not demonstrate the capacity to make this choice. This, too, is a complex issue, as treatment refusal is a patient's right and other factors can influence a patient in refusing treatment. Ongoing pain, medication changes and side effects, anxiety, depression, familial stress, and financial stress can all contribute to refusal of treatment, yet none of these on their own necessarily merit a loss of decision-making autonomy. Typically, a physician or psychologist will sort through all of the factors influencing treatment refusal and determine if any one, or any combination of reasons, rises to the level of concern that merits seeking formal assistance (Hanson, et al., 2005). Depending on the outcome of such evaluation, the program may determine that the team seeks the assignment of a guardian through a formal legal process with the probate court.

A major goal of TRR is restoring the decision-making capacity of those being served in the program. In the most successful situations, individuals being served go from being passive participants in their rehabilitation, to being the leader of the team, setting their goals, and indicating their desires for their treatment and lifestyle choices.

Decision-making capacity, while simple in concept, is a complex issue that has serious implications for the success of the TRR experience. Professionals practicing in this area of medicine experience the unique challenge of adjusting treatment and relinquishing a parental style of treatment direction as the patient gains the ability to take on decision-making capacity.

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Author Bios

Margaret Kroese, MSSW, is the Executive Vice President of Hope Network Neuro Rehabilitation, a large post-acute and transitional residential rehabilitation provider located in west and central Michigan. She has served in this leadership role at Hope Network since 2002 and in brain injury rehabilitation since 1994. Ms. Kroese currently sits on the Executive Board of the Coalition Protecting Auto No-Fault and recently finished her term as the Past-President of the Michigan Brain Injury Provider's Council. She has spoken at various workshops and conferences on the topic of brain injury rehabilitation, Michigan Auto No-Fault and the Affordable Care Act.

Martin J. Waalkes, PhD, ABPP, CBIST, is a licensed psychologist who has been treating individuals with brain injury and spinal cord injury since 1990. He is a board-certified Rehabilitation Psychologist, as well as a Certified Brain Injury Specialist-Trainer. Dr. Waalkes is Director of Neuro Rehabilitation for Hope Network Neuro Rehabilitation where he is responsible for the development of programming and clinical services for transitional residential rehabilitation programs. He is a past vice-chair of the Michigan Board of Psychology, and has a doctoral degree in clinical psychology from Michigan State University. He is the Hope Network psychology department supervisor, providing clinical supervision and direct service in behavioral evaluation, individual therapy, cognitive and neuropsychological assessment, consultation, and support to patients and their families.

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