

The Role Caregiver Support Plays in Client Progression in Therapeutic Recreation Interventions

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HSS 490: Senior Honors Project

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April 22, 2022

Abstract

The purpose of this investigation is to examine how familial and caregiver support systems during recovery from acquired and traumatic brain injury impact client recovery in therapeutic recreation. Familial social support in therapeutic settings has the potential to motivate, support, and encourage clients, but does a strong support system from family, friends, and caregivers improve therapeutic outcomes? I seek to understand the positive and negative implications family support has on client progression and outcomes in inpatient post-acute settings. My investigation seeks to navigate the multiple dimensions caregiver and family dynamic bring to the recovery process. Research will center on navigating shifting family structure, scheduling, and familial well-being through the rehabilitation process. Observational research will be conducted at the Sticht Center at Atrium Wake Forest Baptist Hospital in the acquired brain injury inpatient rehabilitation. The inpatient acquired brain injury rehabilitation program at Atrium Wake Forest Baptist Medical Center provides specialized, intensive rehabilitation services for patients age thirteen and older who have traumatic and nontraumatic brain injuries. This investigation will research how family and caregiver support, or the lack of support, presents barriers in rehabilitation settings. Through research and observation, I seek to attain a comprehensive understanding of how familial support improves or inhibits overall client progression and outcome while analyzing the numerous barriers presented.

Keywords: caregiver support, recreational therapy, familial social support, brain injury

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Physical medicine rehabilitation is a medical specialty that involves restoring function for a person who is disabled as a result of a disease, disorder, or injury (Johns Hopkins, 2021). The primary purpose of inpatient rehabilitation is to return the patient to their highest level of independence following injury. Typical diagnoses that require intensive inpatient rehabilitation with a neurorehabilitative focus, include traumatic brain injury, cerebral vascular accidents, brain cancer, motor vehicle accidents, and gunshot wounds. The average length of stay varies from 14 to 21 days, dependent on diagnosis. Patients assigned to the Acquired Brain Injury unit at Atrium Health Wake Forest Baptist hospital typically stay longer in acute care areas prior to their arrival for inpatient rehabilitation.

The J. Paul Sticht Center on Aging and Rehabilitation at Atrium Health Wake Forest Baptist provides specialized, intensive rehabilitation services for patients aged thirteen and older, who experience traumatic and nontraumatic brain injuries. Individuals admitted into inpatient rehabilitation are required to partake in a minimum of three hours of daily therapy, five times a week. Therapeutic services provided to clients include occupational therapy, speech-language pathology, and physical therapy, alongside other services, such as assistive technology, recreational therapy, neuropsychology, nutrition, rehabilitative medicine, and personalized social work. The requirements for admission to the acquired brain injury unit at the Sticht Center include patients who have a combined need of more than one type of therapy, the presence of an established social support system, and the maintained stability in vital signs, along with personal willingness to participate in three hours of therapy daily.

According to research conducted by John Hopkins Medical University (2022), a variable determining the efficacy of the rehabilitation process is the existence of familial and social support. Numerous determinants contribute to the success of inpatient rehabilitation, such as the level of severity of the injury, age at onset of diagnosis, premorbid health, and lifestyle. In

addition, critical factors, such as the premorbid social determinants of health (i.e, economic stability, education access and quality, healthcare access, neighborhood and built environment, and social and community context) affect the outcome of a client's recovery. While familial support in therapeutic settings possesses the potential to motivate, support, and encourage clients, do strong social support systems ultimately determine a patient's rehabilitative outcome?

Although strong support systems are often associated with familial ties, social support systems include individuals who are able to provide physical assistance, resources, psychological assistance, and a positive outlook regarding the future. Therefore, during my observation, I sought to determine the effect of family dynamics on inpatient outcomes within recreational therapy. The sociocultural evolution that shifts away from ideology of the nuclear family has positively morphed the image of who makes up a family and a social support system. In the modern day, support systems include co-workers, social workers, relatives, parents, friends, caregivers, children and grandchildren, medical team staff, civic groups, school system staff, and governmental agencies. The measurement of who is included in a support system has broadened as the idea of who makes up a family has transformed. Nonetheless, the benefits of having a strong support system during inpatient rehabilitation are unparalleled. According to a study from Johns Hopkins Medical University (2022), "The benefits of having and using personal support systems include reduced stress, decreased physical health problems, and improved emotional well-being" (p. 2).

Barriers

Family structure can be significantly uprooted following a family member's brain injury. During the acute phase of the rehabilitation, family members and caregivers begin to emotionally process the realities presented by their family members' brain injury. In the subacute phase,

caregivers and family members work through scheduling changes, increased stress levels, and confusion regarding the rehabilitation process. For the patient and their family members, the transitional period between the initial onset of diagnosis and inpatient rehabilitation can be upwards of one month (Tardif et al., 2017). During this journey through medical rehabilitation, the family and patient are faced with multiple complications.

The strength of a family support network is not solely dependent on the premorbid quality of relationship, proximity in family relationship, or willingness to partake in medical care. Rather the essential element is the ability to access the necessary resources to provide needed care and support. Whether a family network system is secure prior to the onset of injury of their family member pales in comparison to the family having access to the necessary resources needed to provide care and support to their family member following injury. The variables of resources needed to offer social support include access to viable transportation means, financial resources, medical insurance coverages, access to a telephone, flexible work scheduling, and when necessary, access to childcare services. Spouses of hospitalized patients immediately face the burdens of navigating health insurance approvals, loss of career, losing insurance coverage, and the immediate onset of responsibilities pertinent to maintaining home and family life.

Financial

Financial burdens can present barriers when the injured patient is the primary source of income for the family. The loss of income can wreak havoc and perpetuate the existing stressors faced due to the significant injury experienced by the patient. Financial burden is felt by families when insurance companies decline, limit, or reduce services or equipment for their family members. Although options for disability insurance for severely injured patients are available,

the lengthy application process can take months. In the interim, families must find alternative sources of income to ensure their financial obligations are met. Families with low socioeconomic status and those living from paycheck to paycheck are jolted when faced with the loss of income. In observation, I witnessed numerous families face repossession of vehicles, pre-foreclosure on homes, and loss of jobs as a direct result of a significant and often horrific accident which caused sustained injuries to their family member.

Transportation

This time period can be very detrimental as families must balance spending time visiting the hospitalized patient, managing work schedules, transportation, children's schedules, and family life. Clients in recovery at the Sticht Center originate from as close as the Triad region of North Carolina to as far away as the Republic of China. During my observation, significant transportation barriers were presented for families as their loved one was hospitalized when the patient was visiting on winter vacation. Barriers presented by transportation issues impact social support during inpatient rehabilitation when family members are unable to visit guests during their lengthy stay. The significant increase in gas prices has perpetuated transportation barriers for caregivers. According to AAA of North Carolina (2022), gas prices in the city of Winston-Salem, North Carolina, have increased from an average of \$2.56 per gallon in 2021 to an average of \$3.93 per gallon in 2022. This significant increase has stranded caregivers unable to commute daily to the hospital, while reducing visits for many unable to face the significant cost of filling up. The increase in the cost of transportation reduced the number of family visits, as guests opted to visit weekly instead of daily.

Addiction

The consistent stressors felt by family units overflowed into recreational therapy sessions as family members sought guidance regarding discharge planning, questions regarding disability insurance, and information regarding Medicaid health insurance approval timelines. With desperation, families reached out to treatment team members to seek answers about insurance and financial matters that would be more appropriate for a social worker. Nontraditional families experience the apex of difficulties as familial strain and dysfunction present tension and conflict in therapy session programming. A profound observation that was representative of the role premorbid familial influence plays was witnessed as a grandfather in his nineties¹ struggled to care for his granddaughter recovering from surgery. Throughout her treatment, the grandfather stated it was his obligation to be present twenty-four hours a day, without rest, since his daughter was unavailable as a result of her active addiction to opioids.

The grandfather was unable to drive and relied upon friends and family to bring clothing, food, toiletries, and medicine to the hospital. Despite a lengthy inpatient stay, he never left the hospital or his granddaughters side, using the patient's bathroom to shower, and bedroom chair to sleep in. The patient's mother was unable to visit for family education training or to support her daughter as she navigated a recent diagnosis of a metastatic brain tumor. A 2013 study found that substance dependence among family members is associated with a significant burden for the family (Mattoo, 2013). Aside from a substantial caregiver burden, active addiction of a family member increases conflict, financial burden, disruption of family routine, decreased family leisure, and disruption of family interaction. Families dealing with the active addiction of a family member are both physically and mentally impacted as a direct result of their family

¹ To protect patient confidentiality and remain in compliance with HIPAA, any patient identifying factors in this paper have been modified, including name, gender, age, and any other unique information specific to an individual. The information within this paper was obtained through assessment conducted by the recreational therapy student intern, the patient's medical record, information from treatment team meetings, and the observations and interactions by the intern.

member's addiction. During inpatient rehabilitation, pre-existing familial conflict such as addiction-associated burdens are compounded by the trauma of recovery from substantial injury.

Depression

Following a diagnosis of acquired and traumatic brain injury, the probability of experiencing depression significantly increases. A 2018 study revealed that depression is one of the common psychological sequelae of traumatic brain injury, with as many as 56% of individuals having symptoms of depression at the ten-week post-injury mark (Singh). Following traumatic brain injury, depression can limit the ability to return to work, contribute to the onset of dementia, and worsen cognitive function (Bodnar et al., 2018). Lack of family and social support perpetuates the viability of experiencing significant depression following diagnosis of an acquired or traumatic brain injury. There were numerous patients who did not receive visitation from family or friends during their lengthy inpatient hospitalization. Oftentimes, the only visitation patients received was on their final day, as family members came to pick up the patient to take them home. During recreational therapy sessions, a mother of five adult children disclosed how she felt sad that her sons were unable to visit her during her hospitalization. The lack of social support set forth significant symptoms of depression in which she proceeded to lose interest in therapy sessions, ate significantly less food, and consistently fatigued easily.

The physiological impact on social support was measured in a study of patients living with heart failure conducted by a group of cardiologists. The study found that social support and social integration in the rehabilitation phase of heart failure offered a plethora of benefits. The researchers found that the social support system offset the pathogenesis of stress which positively impacted the neuroendocrine system and the autonomic nervous system response (Luttik et al, 2005). Patients with strong social support systems had a higher positive affect, which lowered their neuroendocrine response while

simultaneously lowering the pathogenic response to stress. They found that patients with strong social support systems had lower stress activation responses in comparison to participants who lacked a social support system.

Sars-Cov2 Pandemic

The 2019 Sars-Cov2 pandemic perpetuated the inability for familial and social support in rehabilitation settings when family and caregivers were banned from visitation at Atrium Health Wake Forest Baptist. Visitation restrictions continued throughout my observations as the lingering omicron variant limited visitation, increased regulations on personal protective equipment and temporarily banned recreational therapy programming, including animal assisted therapy, aquatic programming, and community integration programs. According to a study conducted by Creutzfeldt (2020), the inability to be present for family members who were not infected by Sars-Cov2 created feelings of failure to protect and support loved ones. "The inability to be physically present for their hospitalized family member created anxiety, sadness, uncertainty and a need for more information and updates on the family member's condition" (Hugelius et al, 2021, p. 3.2). The strict visiting guidelines decreased accuracy in patient individualized treatment plans and overall outcome, as treatment teams were unable to triangulate information for assessment questions. Visitation restrictions presented barriers as family members were not present to advocate for medical decisions of their loved one and pertinent caregiver and family hands-on caregiver education was missed.

Influence of Co-morbidities on Client Outcome

An important variable that impacts patient rehabilitation is the patient's previous medical history, coexisting diagnosis, and premorbid lifestyle. Clients with significant comorbidities upon admission must be concurrently treated alongside their referring diagnosis. For example, clients who need dialysis must continue their tri-weekly appointments alongside their required inpatient rehabilitation therapies.

Patients with diabetes are unable to eat meals without insulin checks prior to mealtime, which creates barriers when guests become hungry but must wait for blood sugar testing prior to eating their meal. Comorbidities influence progress in rehabilitation when patients experience ongoing side effects of treatment. Mental health comorbidities are common among traumatic brain injury survivors as they face the trauma presented by severe injury. A 2018 study of post-9/11 veterans in the care of The Department of Veterans Affairs, found that mental health comorbidities such as post traumatic stress disorder impacted long-term outcomes in community reintegration, including social and family connection (Pugh et al, 2018).

There was a striking influence on client progression in treatment based on the number of comorbidities of the patient upon admission. Patients with significant medical conditions had difficulty participating in the minimal three-hour therapy requirement. Patients receiving dialysis of the kidneys proved to be the most taxing treatment experienced by patients, as treatment could last up to six hours. Individuals receiving dialysis treatment often missed their dinner meal and returned to the acquired brain injury unit very late in the evening, leaving them exhausted and hungry. Another variable that directly influenced client progression was off-unit medical procedures.

Ideally, patients leave the hospital without needing further minor surgical procedures for the removal of staples, percutaneous endoscopic gastrostomy tubes, nasogastric tubes, and gastric jejunal tubes. Typically, these procedures were scheduled on site, very early in the morning, prior to the patient's discharge date. Following surgical procedures that required anesthesiological intervention, patients struggled with engagement and motivation for therapeutic sessions. There was a significant increase in declined therapy sessions following surgical procedures as patients reported fatigue due to the lingering side effects of anesthesia.

Influence of Pre-morbid Lifestyle

During my observation, I noted numerous lifestyle choices that impacted patient treatment and outcome. As a reputable medical treatment center, Atrium Health Wake Forest Baptist stresses the importance of creating a tobacco-free campus. During patient hospitalizations, patients are unable to smoke tobacco, vape, dip, or chew tobacco products. Patients with known addictions to tobacco, or any mind-or-mood altering substances, are offered nicotine replacement patches in combination with medicine to assist with withdrawal. Patients experience difficulty when they are faced with withdrawals as they are in recovery from significant brain injury. Family support can encourage or inhibit consistency in maintaining a substance-free environment for the patient.

An observation of when a patient's lifestyle impacted their outcome was when I witnessed a patient's significant other sneak the patient outside the facility to smoke cigarettes. The patient had significant injuries including broken ribs, non-weight bearing status on his left lower extremity, and second degree burns on his arms and hands. The staff immediately explained how it was a breach in hospital policy to the family and patient. The next day, the family members snuck the patient out again to smoke cigarettes at the patient's request, and the doctor immediately discharged the patient for noncompliance to hospital protocols. This encounter significantly impacted the patient's outcome as his hospitalization was significantly shortened, his support system did not receive caregiver or transfer education, and the patient was unable to work on their goals including ambulation, increased activities of daily living, and improving activity tolerance. Furthermore, numerous liabilities are presented when patients with significant injuries are removed from medical settings sooner than expected, including the possibility of reinjury, falls, and death.

Patients' lifestyle prior to admission influenced progress in recreational therapy interventions as physical limitations, due to sedentary lifestyle, limited the amount of physical activity the patient could participate in. Patients living with obesity, hypertension, hyperlipidemia, and anemia as comorbidities

were monitored to ensure safety during implementation of interventions. Vital sign monitoring during therapy sessions was needed for patients experiencing high levels of blood pressure. Following testing, if a patient's vital signs showed their blood pressure was too high, their therapy session came to a halt as the nursing staff needed to intervene. Patients with increased need for medical monitoring had higher cancellations of therapy sessions due to the increased amount of medical interventions, medical procedures, and nursing modalities required.

Family as the Primary Motivator

Social support systems are frequently the source of motivation for patients progressing through treatment. Despite challenges caused from intensive daily therapy, it was commonplace to observe patients, of child-rearing age, who used their children as their primary motivator. A significant observation was made when a young mother used her children as her source of strength. The mother had not seen her three children in over two months when she was admitted into the inpatient rehabilitation. She consistently stated in therapy sessions how much she missed her children and how she was excited to return home to them following her treatment. As her therapy progressed, she grew frustrated that she had not been able to see her children and acted out in anger. As recreational therapists, we saw the unique opportunity to set up a leisure education activity, where we created a modality centered around activities that she could complete post discharge with her children. As a surprise, we invited her husband to bring her children to the hospital to complete the activity together. The patient was elated, and from that day forward she was ignited with encouragement for completion of her therapy goals.

Family Acceptance of Rehabilitation Process

During my observation I was able to see how the premorbid family dynamic impacted patient well-being during their inpatient stay. Although familial support during inpatient stay can create familiarity and comfort for the client, the dynamic of relationships the client had with guests prior to

injury can produce anxiety, stress, and animosity in the patient. A notable example I witnessed during observation was the wife of a patient who was prescribed a nasogastric tube feeding due to his refusal to eat. I witnessed the wife yell, badger, and persistently insist on the patient eating solid food at lunch time. She raised her voice, made gestures, and tried to feed the client despite his clear instruction that he was not hungry or interested in eating. The wife of the patient became so angry at the client she told him, "you are going to die if you do not eat". The patient grew agitated and began to yell back to his wife for her to, "shut up". The medical team made the decision that the negative environment created by the wife was toxic for the well-being of the patient and put a limit on allotment of visiting hours for the wife.

The stress that the patient's family members feel can be redirected towards the staff members of the hospital. Family members of patients who survived horrific motor vehicle accidents may seek to continually protect their family members, viewing difficult therapy sessions as cruel, unneeded, and unwanted. Initially, the therapy process can be taxing and tiresome which may be hard for family members to view, as their family members may experience difficulties. Treatment team members must influence social support networks towards becoming an ally in the therapeutic process by offering consistent communication that alleviates confusion regarding the rehabilitation process.

The misunderstanding of the inpatient rehabilitation scheduling can perpetuate confusion amongst family members since the therapy schedule changes daily based on client needs. If patients are unable to successfully complete sixty-minute sessions, their sessions are cut in half to thirty minutes and scheduled once in the morning, and again in the afternoon. The constant coming and going to therapy sessions can seem overwhelming. Initially, the first few days at inpatient rehabilitation can produce extreme fatigue in patients. Despite their desire to rest and sleep following sessions, they are required to complete their scheduled three hours of therapy daily in order to meet the predetermined standards for

treatment. Although pain and medical considerations are given for cancellation of therapy sessions, fatigue is not significant enough for revocation of appointments.

Patients who do not receive a consistent amount of family visits or support can feel an increased level of pressure to perform successfully during therapy sessions. The extra attention of family members observing during sessions can be un conducive to recovery due to increased stress, over exertion during tasks, and distraction of family while carrying out assigned therapeutic tasks. A study of patients in recovery from myocardial infarction found that family values regarding physical rehabilitation influence the perceptions of hospitalized patients. For example, if a family stresses and values physical activity during their home life, the patient will be significantly more active in physical activities during the rehabilitation process (Birtwistle et al, 2021). The lack of familial visits introduces time constraints for treatment team members who must complete family education, community reintegration education, transfer training, and review environmental barriers in the patient's family prior to discharge. When patients lack consistent visitation from their social support system, familial and caregiver education can be overlooked.

Familial support in therapeutic settings has the potential to motivate, support, and encourage clients, but the family and social support network must promote a productive environment. Social support networks who comprehend realistic goals for the patient, motivate patients, and create supportive environments influence the outcome of treatment and progress in the patients' individualized care plan. When medical teams create allies, instead of adversaries, amongst caregivers and familial support networks, the social support felt by the patient expands.

Comprehension of Hospital Protocols

Another variable of familial support in inpatient rehabilitation is awareness, or lack of awareness, of hospital protocols. During my observations, I witnessed family members completing bed-

to-wheelchair transfers, unaware of the high risk for reinjury experienced by patients impacted by brain injury. Family members, with the good intention of making their loved one feel special, would ignore dysphagia status and bring the patient food items they were not medically cleared to eat. I observed blatant disregard for visitation hours and visitor regulations when a fellow staff member at Wake Forest Baptist Hospital attained a traumatic brain injury. Members of the hospital staff used their badges to bombard the locked unit to check in on their fellow associate. The staff member had so many employee visitors in one day that the nurse manager had to disarm staff badges and require a password for entry to the unit.

An alarming observation occurred when a patient refused headache medicine. Since the patient held her own medical power of attorney, the nurse was required to abide, and not administer the medicine to the patient. As the nurse left the room during her therapy session, the patient's daughter pulled ibuprofen out and offered the medicine to her mother to see if she would take it, completely unaware of the regimented hospital protocols for recording and tracking all pharmacological consumption.

Familial Advocacy

During long term recovery following disability, family members offer an unparalleled level of advocacy. A younger brother, and caregiver to an outpatient client that experienced a hemorrhagic cerebral vascular accident, explained his journey researching on the benefits of Botox injections for patients with contractures following stroke. He explained how he continually researches medical journals to find experimental treatments to assist his older brother in his rehabilitation. While navigating the initial discharge following his brother's stroke, he utilized services provided at a skilled nursing facility. He expressed deep regrets for placing his brother into a skilled nursing facility following his brother's discharge, citing his confusion

regarding skilled nursing facilities. He believed that his brother would receive necessary therapeutic services at the skilled nursing facility in a similar manner provided at an inpatient rehabilitation facility. Upon his realization of the lack of services offered, he removed his brother from the skilled nursing facility, moved him into his home, and took charge of his brother's recovery journey.

As advocates, family members offer insight into the patient's interests, preferences, and mannerisms. In cases where communication is impacted due to diagnoses of receptive or expressive aphasia, the social support system of the patient becomes the only avenue treatment team members have to triangulate information regarding the patient. As discharge nears, the need for patient advocacy grows as plans are drawn. Following brain injury, patients are often regaining their ability to make decisions, problem solve, and recall. Acting as advocates for the patient, family and social support systems work to assist with the patient's deficits in executive functioning.

Discharge

Following discharge, family members are presented with financial, caregiver, and career challenges. In the initial months following discharge of their family member, caregivers notably report symptoms of isolation, caregiver burden, and depression. Despite the patient's needs and medical referrals, continuation of therapeutic services and home health care resources following discharge may be financially out of reach for families. Depending on the severity of the injury, referrals to skilled nursing facilities for continued inpatient treatment may be initiated by the medical team. Only under extenuating circumstances will insurance companies cover skilled nursing services following a lengthy inpatient rehabilitation stay. When services are covered, placement into skilled nursing facilities can take weeks dependent on patient insurance coverage and availability of open beds.

Following twenty-four hour a day care during inpatient rehabilitation, patients are most frequently discharged to their family members' care. Barriers can present themselves in a significant manner during the initial weeks following patient discharge. The patient's premorbid social determinants of health align directly with barriers faced following release from the hospital. Socioeconomic status, differing ability levels, the region the patient is located in, and viable adaptive resources significantly impact post-rehabilitation care. Economic stability, healthcare access and quality, and environmental access also play a role in continuation of services following patient discharge. Neuropsychologically based studies found that "moderate-to-severe traumatic brain injury caused impairments in the areas of attention, executive functioning, memory, and processing speed in both children and adults during the first year of recovery" (Noggle et al, 2018, p.147).

Clients who have lost the ability to ambulate as a result of their injury must work rapidly to ensure their most basic needs will be met outside of the clinical setting. During my observations, numerous family members of patients struggled to have ramps built on the entryway of their house. Family members shuttered upon the realization that entryways, hallways, and bathrooms were too small to fit a standard wheelchair through. Families with significant physical barriers were forced to remodel their garages into bedrooms to accommodate accessibility issues. The patient's premorbid social and community context influenced the viability of resource allocation since donations for remodeling were traditionally offered through church groups, state vocational rehabilitation organizations, and service organizations. The completion turnaround time for a construction project to improve accessibility within the home lasts months, leaving family members in limbo to ensure their family members' most basic needs are met.

Caregiver Burden

Immediately following admittance to the hospital, designs are established for discharge care plans. Families are forced to amend their daily routine as they create plans for successful discharge. The National Alliance for Caregiving and AARP found that "at least 80% of long-term care in the United States is provided informally by family members or friends" (Singer et al, 2018, p.12). Numerous considerations must be made including reconstructing architectural barriers that inhibit entrance into homes, establishing care plans for home health, and finding accessible transportation options for follow-up appointments. During inpatient rehabilitation, patients receive around-the-clock care including services that assist with activities of daily living such as bathing, grooming, eating, and toileting. Upon discharge, the responsibility of care is placed on family members and caregivers. As the planned discharge date nears, the presented responsibilities weigh heavily upon families and caregivers as they take ownership of care. A study of caregiver involvement during the rehabilitation process found that increased practice and participation of caregivers leads to improved exercise function, activity, and participation (Tijssen et al, 2019). Increased participation of social support networks proved beneficial as the study revealed improved quality of life for both patient and caregiver, shorter length of stay in clinical settings, and reduced levels of caregiver burden.

Prior to discharge, families and caregivers begin to experience caregiver burden as the realities of responsibilities are realized. Although attempts to facilitate the least restrictive environment for discharge are made by the treatment team, some patients are discharged home while incontinent of their bowels, using gastric tube feeding for nutritional needs, and under a non-weight bearing status. Patients with significant injury at discharge rely on caregiver assistance to meet their most basic needs. Transition from clinical settings to the home environment presents significant role changes within families including role reversals. In

observation, I witnessed retired parents return to nurturing their adult son, and grandmothers navigate a plan of care for their grandchild's return home. Shifting roles, paired with the financial and psychological difficulties presented, can make adapting to a home environment a complex journey. An assessment conducted by Marsh et al. (1998), found that caregivers of traumatic brain injury patients reported clinically significant levels of psychological distress in the first six months following varying levels of brain injury. Caregivers are at increased risks for anxiety, depression, poor social adjustment, and increasing social isolation.

Analysis of Findings

Familial and caregiver support systems during recovery from acquired and traumatic brain injury positively impacts client recovery, and ultimately overall outcomes in recreational therapy interventions. Aside from increased participation, patients with effective social support systems demonstrate increased motivation as a direct result of the support and encouragement received from their support network. Patients with robust social support systems have an increased likelihood of having allies to assist with post discharge planning, and advocates who ensure the questions that need to be asked are asked. Despite the numerous and multifaceted barriers presented to both patient and family member during the rehabilitation journey, patients with strong familial and caregiver networks are less physiologically impacted by stress and are therefore more prone to engage in therapeutic recreation interventions.

Despite premorbid familial dynamics, lack of comprehension of hospital protocols, and the unrealistic expectations placed on patients, having a social support system in inpatient rehabilitation settings far outweighs the negative consequences of isolation in clinical settings. Patients who lack support during hospitalization face isolation, loneliness, and increased chance of developing depression. Individuals facing the trauma of serious and life-altering injury need

support, advocacy, and encouragement. Medical teams must strive to create surrogate support networks for patients and families who are presented with barriers due to significant injury of a family member. Medical facilities seeking to increase patient support must make strides to diminish the barriers presented to family and caregiver support systems to ensure education, resources, and support are established for the patient in a timely manner. Overwhelmingly, my observations pointed toward a strong social support system increasing potential gains and overall outcomes of clients in recreational therapy interventions.

References

- American Automobile Association.(2022). North Carolina average gas prices. Retrieved 3 Apr. 2022, from: <https://gasprices.aaa.com/?state=NC>.
- Birtwistle, S. B., Jones, I., Murphy, R., Gee, I., & Watson, P. M. (2021). Family support for physical activity post-myocardial infarction: A qualitative study exploring the perceptions of cardiac rehabilitation practitioners. *Nursing & health sciences*, 23(1), 227–236. Retrieved February 2, 2022, from: <https://doi.org/10.1111/nhs.12806>
- Bodnar, C. N., Morganti, J. M., & Bachstetter, A. D. (2018). Depression following a traumatic brain injury: uncovering cytokine dysregulation as a pathogenic mechanism. *Neural regeneration research*, 13(10),1693.
- Creutzfeldt, C. J., Schutz, R. E., Zahuranec, D. B., Lutz, B. J., Curtis, J. R., & Engelberg, R. A. (2021). Family presence for patients with severe acute brain injury and the influence of the COVID-19 pandemic. *Journal of palliative medicine*, 24(5), 743-746.
- Hugelius, K., Harada, N., & Marutani, M. (2021). Consequences of visiting restrictions during the COVID-19 pandemic: An integrative review. *International journal of nursing studies*, 121, 104000. Retrieved February 2, 2022, from: <https://doi.org/10.1016/j.ijnurstu.2021.104000>
- Inpatient rehabilitation. Atrium Health Wake Forest Baptist. (n.d.). Retrieved February 27, 2022, from:<https://www.wakehealth.edu/Specialty/p/Physical-Medicine-and-Rehabilitation/Inpatient-Rehabilitation>
- Luttik, Marie Louise MSc, RN; Jaarsma, Tiny PhD, RN; Moser, Debra DNSc, RN; Sanderman, Robbert PhD; van Veldhuisen, Dirk J. MD, PhD The Importance and Impact of Social

Support on Outcomes in Patients With Heart Failure, *Journal of Cardiovascular Nursing*: May 2005 - Volume 20 - Issue 3 - p 162-169

Marsh, N. V., Kersel, D. A., Havill, J. A., & Sleight, J. W. (2002). Caregiver burden during the year following severe traumatic brain injury. *Journal of Clinical and Experimental Neuropsychology*, 24(4), 434–47.

Mattoo, S. K., Nebhinani, N., Kumar, B. N., Basu, D., & Kulhara, P. (2013). Family burden with substance dependence: a study from India. *The Indian journal of medical research*, 137(4), 704–711.

Noggle, C. A., Dean, R. S. ; Barisa, M. T. (2013). *Neuropsychological rehabilitation* (Ser. Contemporary neuropsychology series). Springer Pub. Co., LLC. Retrieved February 2, 2022, from:
<https://ebookcentral-proquest-com.libproxy.uncg.edu/lib/uncg/detail.action?docID=11792>
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Overview of physical medicine and Rehabilitation. Johns Hopkins Medicine. (2022). Retrieved February 27, 2022, from:
<https://www.hopkinsmedicine.org/health/treatment-tests-and-therapies/overview-of-physical-medicine-and-rehabilitation>

Pugh, M., Swan, Al, Carolson, K, Jaramillo, C., Eapen, B., Dillahunt-Aspillaga, C., Amuan, M., Delgado, R., McConnell, K., Finley, E., & Grafman, J. (2018). Traumatic brain injury severity, comorbidity, social support, family functioning, and community reintegration among veterans of the Afghanistan and Iraq wars. *Archives of Physical Medicine and Rehabilitation*, 99(2), S40-S49.
[https://www.archives-pmr.org/article/S0003-9993\(17\)30413-6/fulltext](https://www.archives-pmr.org/article/S0003-9993(17)30413-6/fulltext)

- Singer, G. H. S., Biegel, D. E., & Conway, P. (2012). Family support and family caregiving across disabilities. Routledge. Retrieved February 2, 2022, from: <https://ebookcentral-proquest-com.libproxy.uncg.edu/lib/uncg/reader.action?docID=1710886>
- Singh, R., Mason, S., Lecky, F., & Dawson, J. (2018). Prevalence of depression after TBI in a prospective cohort: the SHEFBIT study. *Brain injury*, 32(1), 84-90.
- Tardif, P. A., Moore, L., Boutin, A., Dufresne, P., Omar, M., Bourgeois, G., ... & Turgeon, A. F. (2017). Hospital length of stay following admission for traumatic brain injury in a Canadian integrated trauma system: a retrospective multicenter cohort study. *Injury*, 48(1), 94-100.
- Tijssen, L. M., Derksen, E. W., Achterberg, W. P., & Buijck, B. I. (2019). Challenging rehabilitation environment for older patients. *Clinical interventions in aging*, 14, 1451–1460. Retrieved February. 3, 2022, from: <https://doi.org/10.2147/CIA.S207863>